

# Review



**Scene from the Deafblind Unit at  
the Holy Land Institute for Deaf and  
Deafblind Children**

# A message from the President

**D**eafblind International was formerly known as the International Association for the Education of Deafblind People.

DbI Review is published twice yearly, the two editions are dated January and July.

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs are welcome.

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DbI Secretariat  
Able Australia, Camberwell  
Email: [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org)  
Tel: +61-1300-225-369  
DL: +61-03-9046-0555  
M: +61-0413-157-556

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#### Editor

Stan Munroe  
Email: [information@deafblindinternational.org](mailto:information@deafblindinternational.org)

#### Design

Sally Coleman

#### Distribution and DbI Membership

DbI Secretariat  
Email: [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org)

#### DbI Website

Stan Munroe and Secretariat

#### Editorial Office

CDDBA Office, 2652 Morien Hwy,  
Port Morien, NS, Canada B1B 1C6

Email: [information@deafblindinternational.org](mailto:information@deafblindinternational.org)  
Website: [www.deafblindinternational.org](http://www.deafblindinternational.org)

Tel: +1 902-737-1453  
Fax: +1 902-737-1114

**Cover:** Scene from the Deafblind Unit at the Holy Land Institute for Deaf and Deafblind Children

Dear Friends and colleagues,

**T**he Management Committee met in London in March this year. We were delighted to welcome Gary Daly our new Secretariat through Able Australia. It was a great opportunity to meet Gary and generally catch up on the 'workings' of DbI. Clearly Gary came with a lot of knowledge thanks to Matthew, Bronte and the smooth handover from Senses Australia.

At the time of writing we are looking forward to our 9th European DbI conference in Aalborg, Denmark. As ever huge thanks to everyone for all their hard work around these events. I know a number of the Networks are busy organising their activities around the September conference, including Usher, Outdoor, CHARGE and Youth networks. We owe a big thanks to Henriette Olesen who has stood down as our Network Co-ordinator. The Man Com has been discussing the way forward and will report on progress at our September Board meeting.

As ever our colleagues and members are involved in some wonderful initiatives. You will read about the many achievements in the Review. Sadly I can't attend all of them but I do manage some. I had a wonderful week in India in February and as always I was impressed by the amount of work our colleagues in India manage to do and particularly pleased to attend



an art exhibition around the theme of the senses.

I have been in touch with Dmitry and Deaf-Blind Support Foundation Connection and look forward to visiting Moscow in June. We are all pleased that Dmitry's team continue to publish a version of the DbI Review in Russian. I am also attending a conference in Dublin hosted by Child Vision who are an innovative organisation supporting MHVI children.

The Man Com is delighted to note the America's conference being planned for April 2018 and wish Marianne Riggio and Perkins all the best for this important event.

We continue to link with ICEVI and the WFDB. The World Federation of Deafblind continues their important role of monitoring the Convention on the Rights of Persons with Disabilities.

So all things considered it is a busy time with our administration and governance, our network and conferencing activities and the policy work. All only possible through the hard work and commitment of our Members.

**With Best Wishes**  
**Gill Morbey, DbI President**

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# Editorial

Welcome to the 59th Edition of DbI Review.

We are presenting once again another full edition featuring an eclectic array of articles which I hope you find appealing. As deafblindness is a unique disability, the articles presented in this edition are themselves unique in their topical material.

This edition begins with a special salute to Christiana Salomie upon her retirement from a storied career serving children with deafblindness in Romania. When Cristiana first met deafblind children in Romania's orphanages and long-stay hospitals twenty years ago, she was horrified by the conditions they were living in. She was passionately determined to do something about it. Her activities subsequently played a key role in changing the lives of hundreds of children and adults. Most recently, Christiana is remembered for spearheading the 15th DbI World Conference in Bucharest in 2015.

The next two articles in this edition are from the Canadian Deafblind Association Ontario Chapter and from Brazilian Daniella Forchetti. In my opinion they are brilliant in showing that such arts as music and dance can serve as incredible multisensory tools to enhance the lives of individuals who are deafblind. Anyone attending the DbI Conference in Brazil in 2011 might remember Daniella's dancers performing at the closing ceremonies.



When I initially received the article "From Mylar Hats to the Classroom" I was at first puzzled with the title until realizing that the author Paige Furbush represents another in the growing list of family members of disabled persons who chose careers connected to their personal life experiences. Paiges' closing comments were very pertinent: "I sincerely hope that by educating other professionals, community members, and my students' parents to help them better understand and advocate for their children and their needs, it can help to change the current narrative for children who are deafblind. Without widespread understanding of how to reach these unique children, we will continue to see professionals and community members turn their backs on them simply because they feel unequipped to 'handle' them."

A most welcome feature article comes from the UK titled: Developing Awareness of Deafblindness in Health and Social Care Provision for Older People. The authors conclude that: older people who are deafblind are likely to be

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# Vice Presidents' Messages

## BERNADETTE M. KAPPEN REPORTS:

I am sending you this message as we celebrate Deafblind Awareness week in the United States. The field and the advocacy efforts on behalf of individuals who are deafblind have come a long way over the past 30 years. We have so much to celebrate. Individuals who are deafblind are recognized for their skills and abilities. They are in the workforce, living independently and being offered quality programs to meet their needs.

As we reflect on this, we need to look to the future and identify where the gaps still exist. Awareness is key. Even with the success in many areas of the world in having deafblindness identified as a unique disability there are still many countries struggling to have children and adults receive the services they deserve.



The current DbI strategic plan is focused on helping to close the gap. I have had the pleasure of working with

Graciela Ferioli to begin working on an awareness campaign to help promote deafblindness in countries not yet connected to DbI. Over the next few years, the website will grow to offer help and assistance to professionals, parents and individuals who are deafblind. Not everyone can attend conferences but they can be connected and receive the information they need to encourage the development of service. When possible, small gatherings of individuals will

occur to discuss needs and offer support. Graciela will also be interacting with the Networks to help with communication and sharing of knowledge.

The Awards Committee would like to remind you to be thinking about individuals who you would like to nominate. The DbI Americas Network will host a conference in April 2018 in Hyannis, Massachusetts. This would be an opportunity to honor individuals with the Life Time Achievement Award, the Distinguished Service Award and the Young Professional Leader Award. Please begin to think about this and refer to the website for information on nominations.

**Bernadette M. Kappen**  
([bkappen@nyise.org](mailto:bkappen@nyise.org))

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## FRANK KAT REPORTS:

The past year will be remembered as the year in which we fleshed out the details of our three-point policy. At our meeting in Orlando we agreed we need to focus on Diversity, Social Media and Technology and Networks.

By 'fleshed out', I mean that we have progressed from describing objectives to taking action! Each point has been given a concrete description that includes the necessary budget allocation

The Diversity working group will make the first concrete proposals to achieve our objective of promoting diversity in our organization. I'm very pleased that Graciela Ferioli will help us with this task. Member's ideas are most welcome to assist us with implementing our policies.

During my time at DbI, and sometimes in combination with my work for Kentalis, I have noticed two major changes in the deafblind



field. The first major change I noticed while at recent meetings I attended in Brussels and Vienna, was that society is

demonstrating a growing interest in inclusion. This development of course is being driven by people who are deafblind themselves. We can't forget also that the International Convention on the Rights of Persons with Disabilities is now making more progress in this matter. This Convention reaffirms that society should be ensuring that every person be a full member of it. Offering separate 'special education and care' only, without the possibility of a truly free and informed choice, is therefore in conflict with this UN convention. In our work at DbI, this means that this issue

involves all of us, including improving our processes in this regard.

The second change concerns Information, Communication and Technology (ICT). While it is important in our own member organizations, ICT is a critical tool to enhance the autonomy and empowerment for deafblind people.

Further to this context, last November I and many of my colleagues participated in the 'Communication in the context of congenital deafblindness' conference in Groningen. I observed that the level of our knowledge, the workshops and the work meetings was very high. This is a result of the sound collaboration and the sharing. I know that this will also be the case during the 9th European conference in Aalborg, Denmark. I will be delighted to see you all there, getting ready for the future!

**Frank Kat** ([F.Kat@kentallis.nl](mailto:F.Kat@kentallis.nl))

# Cristiana's Amazing Intervention

**Cristiana Salomie, who retired as the Director of Sense International Romania in March, has seen big changes in her country in the last 20 years.**



Cristiana speaks at the DbI conference in Romania

**T**wenty years ago, when Cristiana Salomie first met children who were deafblind in Romania's orphanages and long-stay hospitals, she was horrified by the conditions they were living in. She was passionately determined to do something about it, and as the first Director of Sense International Romania<sup>1</sup>, played a key role in the development of early intervention, inclusive education and vocational services – which have changed the lives of hundreds of children and adults.

Cristiana retired in March and is delighted to be passing the baton to her long-term colleague Edelka Czondi. She spoke to Colin Anderson about the challenges and many joys of her amazing journey.

## How did it start?

Cristiana worked as a language teacher for 20 years, and during that time

taught a few deaf pupils, who were often written off by the other teachers.

“My first pupil, who was deaf, was an extremely clever girl whose parents decided for her to be educated in a mainstream school,” she says, “and because they had the resources and were extremely conscientious parents they took the risk. But it was an extremely difficult job for me as a class teacher and I struggled a lot. It was very hard because at the end of each term I was told by

my colleagues that because of that girl the whole class hadn't done so well. I never forgot that.”

These were difficult years, with the whole country living under Ceausescu's 'plague of fear', as Cristiana describes it. After the revolution in 1989, Cristiana volunteered as a translator and supported Nev Jeffries, and then Richard Turner, head of the British Red Cross in Romania. They travelled across Romania delivering medicine, toys and food for children but

<sup>1</sup> <http://surdocecitate.ro/en>

## Christiana's Amazing Intervention

were dismayed by the corruption and neglect they found. "We met one child in a long-stay hospital who was in the same room as an old man and everything was so awful," she says.

Later, with funding from RNIB<sup>2</sup> and RNID<sup>3</sup> (now Action on Hearing Loss), she and Nev, and then Richard, visited schools for hearing and vision impairments across Romania – and her knowledge and experience grew. It was at the Romania School for the Blind in Bucharest that she met Paul Ennals (now Sir Paul Ennals) from Sense and her long association with Sense International began – with her appointment as Director for Romania in 1997.

There was a mountain to climb. "I had to start from scratch," she says. "Nobody had ever heard of deafblindness in Romania. In fact, when Richard Hawkes

(Sense international's first Director) and I started visiting different ministries and associations for the deaf and blind everybody said: "We don't have deafblind people in Romania – but I knew from visiting all those schools that it wasn't true."

During this time, the experience and skills of Sense staff from the UK in working with deafblind people was invaluable. Cristiana pays tribute to the many colleagues who supported her including: Richard Hawkes, Rodney Clark, Emanuela Brahmsha, Mary Foster, Norman Brown and Eileen Boothroyd – to name just a few.

### Training the teachers

One of the key struggles was getting the Romanian government to recognise deafblindness in law, which was achieved in 2006. The

Disability Law 448 recognises deafblindness as a unique disability and entitles people with this disability to appropriate services. "I knew that unless there is a law we can't be successful," she says.

"We had a very, very clear plan and started with education. We developed training programmes and materials for teachers and support staff so they could be highly effective in inclusive education."

The plan at this stage was not to set up new services ourselves – but rather to work with the Ministry of Education to improve the existing system and support and train teachers. "We explained that even though it seems a bit costly," she says, "the ratio of one teacher to one child, and classes of not more than four children were important because if children get help in the early days they have a chance to do something, and not to live on state support for the rest of their lives – which would be more cost-effective in the long run."

Since 1998, around 200 teachers, psychologists, physiotherapists, and 10 national trainers have been trained. And around 500 children have benefitted from specialist classes in state schools.

### The power of early intervention

This was a huge progress, but it revealed a further challenge: "We noticed that rehabilitation was often not possible for children at school age," she says, "if their



Cristiana and colleagues at the Erste awards

<sup>2</sup> <https://www.rnib.org.uk>

<sup>3</sup> <https://www.actiononhearingloss.org.uk>

sensory impairments had not been identified before.

"So we developed partnerships with national and local authorities in four centres in Romania (Bucharest, Oradea, Timisoara and Iasi) so that new-born babies and young children would be screened and tested for hearing and vision impairments. Those that needed support were able to attend one of four Early Support Intervention Centres where they and their parents could receive specialist help."

So far over 103,581 babies have been screened for hearing impairments, 17,049 for visual impairments and 234 children have been identified as having a dual sensory impairment.

This early diagnosis is vital so that sensory stimulation therapies can start as early as possible – with supporting the child to communicate a key priority. A 2014 report on early intervention by Sense International Romania states that: 'Communication is based upon securing a relationship between the child and the people around, as well as on their need to adapt to the environment. Early intervention is focussed on what the child can do, on the way in which they communicate their needs and interests.'

"I have no words to tell you how important early intervention is," says Cristiana. "One of the happiest days in my life was when I met a mother who had been told by the doctors that her son was doomed to be blind. But after

some sessions of multiple stimulation the same doctor changed her diagnosis and could see a much better future for him."

Right from the start, Cristiana also recognised that parents should play the key role in this process. When multidisciplinary teams were created – made up of doctors, ophthalmologists, audiologists and education specialists – the parents were at the centre of this.

There was also a great deal of work to bring families together so that they could learn from each other, offer mutual support and grow in confidence. "There have been so many wonderful sessions where parents have come together with our colleagues," she says.

### Vocation training

As you will have gathered by now, Cristiana is not one to rest on her laurels – and she was only too aware of the next challenge. As the children were growing older and moving through school, their parents and teachers started to express concerns about what they would do in the future, as there was no provision from the government.

So with support from the Orange Foundation<sup>4</sup>, a new vocational project was set up in 2012. Young adults with deafblindness are learning trades, including modern skills like digital topography that will allow them to find a job," she says. Eight vocational workshops have been set up so far, and 162 young adults have received training.

### What has she learned?

Cristiana's life and career has moved over such a changing landscape – from those early classroom experiences to the terrible orphanages she visited; from successfully lobbying the government to developing new opportunities for the 21st century. What has she learned?

"I think if you are to be successful you need passion, perseverance, determination and a clear strategy," she says. "I have also been extremely lucky to have such a loyal and professional team to work with over many years: Etelka Czondi, Ramona Antonie, Andrea Toia, George Salomie, Dana Butuc and previously, Teodora Seiciuc.

Not surprisingly, leaving her colleagues and work has not been easy for her. She's delighted that Etelka Czondi is the new Director as they share the same values, and Cristiana involved her closely in all decision making for the last two years. "Leaving has been gut wrenching for me," she says, "but that is because my work has meant so much to me. I have had a fantastic career, I'm extremely proud of what we have achieved and grateful to all the people who supported me on this journey.

"But I'm happy and confident that Sense International Romania will be in good hands and – together with her fabulous team – Etelka will make sure that everything we've done so far will be sustainable and Sense International Romania will flourish!"

<sup>4</sup> <https://www.fondationorange.com/en>

**EDITOR'S MESSAGE** *(continued from page 3)*

missed by providers of health and social care. This project has demonstrated that delivering training to frontline care staff can lead to real gains in terms of both the support and the identification of people who are deafblind.

Other feature articles include a summary of Saskia Damen's doctoral study on interpersonal communication between individuals with congenital deafblindness and their communication partners; a research study by Occupational Therapy colleagues from Perkins School for the Blind determining the effectiveness of various positioning interventions used to improve the fine motor skills of school-aged children with CHARGE syndrome and/or deafblindness.

This edition presents the fifth in the series of Action Research articles from Dr. Susan Bruce. Complementing Dr. Bruce's article is one from Helle Buelund Selling and Anne Søby demonstrating a practical application of Action Research. Their article (Learning through Action Research) highlights elements from an 'Action Research Project' carried out at the Centre for Deafblindness and Hearing Loss (CDH) in Aalborg, Denmark.

In addition to these feature articles, this edition follows the magazine's tradition of presenting brief reports from the following DbI Networks: CHARGE, Communication, Youth, Outdoor, Usher Syndrome and Research.

Other interesting submissions are organized in the Country Reports section. Articles are presented from Argentina, Australia, Ireland, Jordan, Malawi, Nicaragua, Russia and Switzerland.

Conferences continue to be an integral activity of DbI. By publication time, we will be just weeks away from the 9th DbI European Conference (Touch of Closeness) scheduled in early September 2017 in Aalborg, Denmark. Four of the Networks (CHARGE, Outdoor, Youth and Usher Syndrome) are planning pre-conference events. Details about these are located in the respective Network reports.

In closing, I want to extend my deep thanks to the many collaborators who submit articles to support this valuable publication.

**Respectively,  
Stan Munroe,  
July 2017**



# Individuals who are Deafblind ‘Speak’ through Music Therapy

Brian Shypula

**D**rum mallets pound inches from Nicholas’s face and he is grinning from ear to ear.

It’s a music therapy class at the Canadian Deafblind Association Ontario Chapter Resource Centre<sup>1</sup> in Paris, Ontario and 19-year-old Nicholas has his chin on the skin of a big table drum in the centre of the room. He craves the intense, room-shaking vibrations given off by the instrument during the energetic playing by his peers.

But it wasn’t always this way for Nicholas. When he started coming to music therapy about one year ago he was not able to stay for more than 10 minutes before he would become overwhelmed and want to leave.

“He now not only stays for the entire hour – but actively and independently participates throughout,” said music therapist Amy Di Nino.

Placing his head atop Di Nino’s guitar to feel the vibrations as she strums the strings, Nicholas signs “more” at the end of the song.

“He now expresses his desires and makes choices because he can access the music in a way that is meaningful to him,” Di Nino said.

Just as each individual’s deafblindness is unique, each benefits in different ways from the music therapy sessions.

John Jr. assists his peers and engages with them in a more musical way – both verbally and non-verbally.

“He has grown as a musician and feels comfortable supporting others to do the same,” Di Nino said, describing the leadership skills she sees evolving in John Jr. during the classes.

For Alecia, another of the regular participants, music therapy is a confidence booster. At a recent class, she joined Di Nino in a duet in front of her peers.

“It’s fun for me and I love it for sure,” Alecia said.

The energetic classes are clearly fun but there’s much more to music therapy. Why does it work?

Di Nino, who is an accredited neurological music therapist<sup>2</sup>, says technological advances in the field of brain anatomy and cognitive science such as magnetic resonance imaging have allowed neuroscientists to make significant advances in explaining how the human brain converts sound waves into music. These findings are adding to an impressive



Author Brian Shapula

*“If we think about neurotransmitters such as dopamine – critical to the co-ordination of movement, the regulation of mood and the brain’s reward system – and serotonin – known to regulate mood and sleep – these are both triggered by active and passive music makings...”*

<sup>1</sup> Canadian Deafblind Association Ontario Chapter ([www.cdbaontario.ca](http://www.cdbaontario.ca)) is a large corporate member of DbI.

<sup>2</sup> **Neurologic music therapy** (NMT) is the therapeutic application of music to cognitive, sensory, and motor dysfunctions that come from human neurologic diseases. NMT treatment is based on stimulating music perception and production parts in the human brain, and the effects thereof on nonmusical and behavior functions.

## Individuals who are Deafblind ‘Speak’ through Music Therapy



**Alecia plays the drum table with music therapist**



**John Jr. plays a drum with intervenor**

body of evidence that suggests music can trigger physiological changes far beyond the purely cognitive. “If we think about neurotransmitters such as dopamine – critical to the co-ordination of movement, the regulation of mood and the brain’s reward system – and serotonin – known to regulate mood and sleep – these are both triggered by active and passive music making and have such a powerful influence over mood states and body functions,” she said. There are four steps to how people process sound.

There is an awareness that something has begun to vibrate. It’s followed by how the sound makes them feel, then recognition of the sound and finally comprehension of the sound.

“No matter how isolated one might be within their world, the elements of music – rhythm, timbre, melody, harmony, tempo, meter, texture, dynamics – stimulate the auditory cortex of each individual’s brain, and I cannot think of any other stimuli that does that for each and every deafblind person,” Di Nino said.

Kristi Clark, Special Projects Intervenor at CDBA Ontario, met Di Nino while attending music therapy with a consumer several years ago. “I just saw the overwhelming change in the person’s demeanor and her attitude throughout the evening when we attended,” Clark recalled.

The memory stuck with Clark and she was happy to reconnect with Di Nino to provide weekly music therapy to consumers as part of CDBA



**Greg plays the drum table with intervenor**

Ontario’s special projects intervention programming.

“It has absolutely exceeded my expectations,” Clark said.

Music therapy pushes new boundaries and experiences for consumers.

Each week there are examples of independent behaviour; some spontaneous and some encouraged by Di Nino.

“Sunshine,” sang Matthew, smiling after a dramatic pause, as he finished the line “You are my ...” started by Di Nino.

Everyone cheered.

“Don’t take my sunshine,” sang Meaghan to more cheers.

Other times consumers follow Di Nino’s lead with an instrument such as a hand drum. The music therapist described it as “call-and-response” playing. It may be striking the same number of notes or following her changes in tempo.

Di Nino explained that anticipation, curiosity and imitation are motivators for communication. All are in play during music therapy.

“If they can anticipate, then they’re going to be more likely to communicate,” Di Nino said.

“So here we are having a conversation with consumers who may be non-verbal ... they’re able to understand that we’re playing together and they’re able to express themselves in ways that they wouldn’t be able to do,” she said.

Clark agreed wholeheartedly, citing the experience of participant Allison.

“When Allison first started with music therapy she would become very red in the face and almost shy and almost withdraw when it was her turn,” Clark said.

“But now she is so comfortable, she knows what to anticipate. That is a big thing with a lot of our individuals – anticipation, knowing what to expect, what’s next. Allison, you can see her making those independent choices,” she said.

Both Di Nino and Clark acknowledge the vital role of intervenors during music therapy.

“I can’t emphasize enough with our deafblind men and women participating in music therapy – goals wouldn’t be achieved without the dedication and ‘Do With, Not For’ approach of each and every Intervenor,” Di Nino said.

To help them, Di Nino held special sessions of music therapy solely for Intervenor, leading them through the same types of activities the consumers would experience.

Intervenor Brittany Malcolm and Tarisa DeBoer put the lessons to use, demonstrating quick thinking and creativity with consumer Andreina. Because of the height of her chair,

Andreina’s feet weren’t quite able to reach the floor to tap to the beat of I Will Survive, so the intervenors placed one of Andreina’s feet over their own, moving them to the beat. Instead of hand-under-hand, they called it “foot-under-foot” intervention.

Parents were also treated to a session of music therapy at CDBA Ontario’s annual Parent Conference in Collingwood, Ontario last October.

It inspired one attendee to anonymously donate the Remo Tunable Drum Table that so enralls Nicholas, imported from California.

Parent Patty Coleman said she appreciates what music therapy provides for her daughter, Kimberly, who has no vision and some residual hearing.

“She is very tactile defensive, it’s very hard to get her to do things. This isn’t forcing her to do it but it’s exposing her to it,” said Coleman, who watches and smiles when Kimberly places a hand atop of the drum table or reaches for an instrument held by her Intervenor.

Coleman said she also appreciates the social aspect of music therapy for Kimberly, who is an only child and doesn’t have a lot of contact with others except for her Intervenor and parents.

“It gives her more of a normal life,” her mom said.

“There’s just such a spiritual feel with everyone playing at once,” said Marjorie Odell, one of Kimberly’s Intervenor.

The social aspect extends to other staff who work at the Resource Centre, many of whom duck their heads through the door to observe when they hear the music echoing through the building.

*“So here we are having a conversation with consumers who may be non-verbal ... they’re able to understand that we’re playing together and they’re able to express themselves in ways that they wouldn’t be able to do...”*

Kevin, with intervenor strums the strings of music therapist’s guitar



Nicholas places his head on the neck of the music therapist’s guitar to feel the vibrations from the instrument

## Individuals who are Deafblind ‘Speak’ through Music Therapy



Nicholas, with intervenor rests his chin on the drum table to feel the vibrations



Playing together on the drum table are, from left, Rena, Alecia, music therapist Amy Di Nino, LeeAnn and John Jr

*“There are melodies and rhythms that these men and women need to create that give them and deafblindness a voice within our world...”*

“That’s my favourite day at work, when I can come in and hear everybody having a great time and I get to listen to music all day. There is always great anticipation from all the people who have been to Amy’s classes at the Resource Centre,” said Leah Cameron, Director of Services.

Di Nino had no experience with deafblindness before taking a job with W. Ross Macdonald School<sup>3</sup> in Brantford, Ontario 15 years ago.

“The learning curve was very steep ... it took me at least five years to feel comfortable in my abilities to be connecting effectively through music,” said Di Nino, who received a provincial award for teaching excellence

in 2012 for her work at WRMS and is one of the few music therapists in North America working with individuals who are deafblind.

She is now completing her master’s degree in therapy at Berklee College of Music<sup>4</sup> in Boston, has her own private practice, ADD Music Wellness, and is creating an interactive music book that can be used by educators, Intervenors and music therapists working individuals who are deafblind.

Di Nino encourages other organizations working with individuals who are deafblind to explore adding music therapy. Almost every country and within that, every state or province, has an organization where they can find a music therapist, she said. In Canada, it’s the Canadian Association of Music Therapy (CAMT)<sup>5</sup> and the Music Therapy Association of Ontario (MTAO)<sup>6</sup>.

“Music therapy allows everyone to participate without any experience required. In every music therapy session I observe

deafblind individuals being empowered through music,” she said.

CDBA Ontario held its first-ever Christmas concert in December 2016, building on momentum from the music therapy program. Consumers performed to a packed room at the Resource Centre. Clark said one of her goals is to have more group performances for the public.

“There is nothing better than when the consumer can say, ‘Hey, look at me, this is what I’ve accomplished. This is what I’ve done. I can do this,’” she said.

“There are melodies and rhythms that these men and women need to create that give them and deafblindness a voice within our world,” Di Nino said.

**For more information, contact Brian Shypula, CDBA Ontario Chapter Communications Coordinator at email: BShypula@cdbaontario.com**

<sup>3</sup> [www.psbnet.ca/eng/schools/wross](http://www.psbnet.ca/eng/schools/wross)

<sup>4</sup> <https://www.berklee.edu>

<sup>5</sup> [www.musictherapy.ca](http://www.musictherapy.ca)

<sup>6</sup> [www.musictherapyontario.com](http://www.musictherapyontario.com)

# Di Cavalcanti's girl: an intersemiotic dialogue between painting, dance and audio-description

Daniella Forchetti

## Introduction

The theme of art and accessibility is being increasingly spread around the world, either as a school activity or as a form of leisure. In this paper, the intention is to show how the partnership between dance and audio-description could be another resource in the field of sensorial and cultural accessibility.

The project started by an invitation from the curator of the exhibition Amanda Tojal (PhD) to present a workshop/dance performance at the exposition "*Sentir pra Ver*"<sup>1</sup>, representing the painting named "Untitled" by Emiliano Di Cavalcanti<sup>2</sup>. We selected this piece of art to create another form of communication accessibility as part of the exhibit.

The exhibition was composed of 14 photographic reproductions of art works belonging to the Pinacoteca do Estado of São Paulo<sup>3</sup>. These reproductions were presented with such accessible resources as: sound resources, three-dimensional and two-dimensional reproductions and boards consisting of high

contrast figure / backgrounds to assist the understanding of the works of art.

The exhibition also included, as an accessibility resource, audio-description that stimulates the exploration and interpretation of the selected works of art. Audio-description is considered a modality of intersemiotic translation<sup>4</sup> that allows the translation of the images into words during cultural, sporting, educational or touristic events, allowing participation by visually impaired people. The intention here was to include people with deafblindness, intellectual disabilities, dyslexia, illiteracy and the elderly, to increase the population benefitting from audio-description.

By representing painting through dance, audio-description is used to mediate between the image, movement and words. The first moment was an intermediated performance, with the guide-interpreter as the mediator, listening to the audio-description, then interpreting the performance



**AUDIO DESCRIPTION OF PHOTO OF DANIELLA FORCHETTI:** White-skinned woman with rounded face, short straight brown hair, brown eyes, medium nose, smiling with red lipstick.

for the person who was deafblind. The performance interprets the image for the deafblind audience.

As the researcher and interpreter-creator of the dance, I prepared the audio-description script for the performance. The audio-description narration was performed by another member of the exposition. The guide-interpreter served as the mediator (or intervenor)<sup>5</sup> between the audio-description of the dance and the deafblind persons in attendance.

<sup>1</sup> [https://www.sescsp.org.br/.../50534\\_EXPOSICAO+SENTIR+PRA+...](https://www.sescsp.org.br/.../50534_EXPOSICAO+SENTIR+PRA+...)

<sup>2</sup> [https://en.wikipedia.org/wiki/Emiliano\\_Di\\_Cavalcanti\\_\(Rio\\_de\\_Janeiro,\\_1897-1976\)](https://en.wikipedia.org/wiki/Emiliano_Di_Cavalcanti_(Rio_de_Janeiro,_1897-1976))

<sup>3</sup> [pinacoteca.org.br](http://pinacoteca.org.br)

<sup>4</sup> [https://en.wikipedia.org/wiki/On\\_Linguistic\\_Aspects\\_of\\_Translation](https://en.wikipedia.org/wiki/On_Linguistic_Aspects_of_Translation) (It is the linguistic verbal sign that gives an object its meaning. Interpretation of a verbal sign according to Roman Jakobson, a Russian-American linguist and literary theorist, can happen in three ways: intralingual, interlingual and intersemiotic)

<sup>5</sup> Editors comment

### Methodology

This research was a case study using audio-description of a dance to represent a painting for the deafblind audience.

Using a qualitative approach, it was possible to investigate and be part of the research object at the same time.

Two deafblind adults who use different forms of communication were selected for this research. One of the individuals has low vision and communicates using Tactile Sign Language, while the other is blind and uses a hearing aid. People from a facility the city of São Paulo, Brazil that takes care of deafblind individuals and people with multiple sensory impairment were invited to take part in this workshop.

This experiment was carried out from April to June 2015 at the Memorial of Inclusion<sup>6</sup> located in in São Paulo, Brazil.

### Presentation of the Experience – Work Selection

We selected the work of art of Di Cavalcanti for this research because it would be easy for the researcher to build a narrative to represent the character in the painting along with the other scenic elements.

To assist in the data analysis of the research we used the dance audio-description tools described by Snyder (2015) based on the Laban Movement Analysis (LMA).

Based on the analysis of these instruments we tried to understand how the audio-description of the dance, playing the role of mediator,



FIGURE 1: Untitled, oil with cardboard, Di Cavalcanti, undated

**Image Description:** The Painting represents a young brunette woman with black short hair and black eyes, wearing an orange dress with short sleeves, and a red belt. She sits on a wooden chair, her arms crossed, her head resting on her left forearm, and leaning over a wooden table with a red towel falling on her lap.



FIGURE 2: Presentation of the exhibition “Sentir pra Ver”. Source: Inclusion Memorial. Presentation link: <https://youtu.be/7L3ShUI0c50> (Portuguese version)

<sup>6</sup> [hrising.blogspot.com/.../memorial-da-incusao-em-spaulo-inclusion...](http://hrising.blogspot.com/.../memorial-da-incusao-em-spaulo-inclusion...)

allowed the individuals who are deafblind to get in touch with the painting of Di Cavalcanti, to access enjoyment of the art.

Following the presentation of the dancing performance, the researcher took each of the deafblind individuals to the scenario pictured opposite. Each deafblind person touched the interpreter-creator, who embodies the form of the accessible work of art, with the guide-interpreter following the progress.

The expression “embodiment of the word by example” is found in Paulo Freire’s *The Pedagogy of Autonomy* (1987, p.16). In the case of our study, we translated into context: the interpreter-creator exemplifying the work of art for each of the deafblind individuals, in a three-dimensional and realistic fashion. The deafblind person, individually, can create his

or her own mental image of the work through the combination of touch and audio-description.

According to Tojal (2007, p. 103), The strategies of mediation that lead to the multisensorial perception applied to the educational action in museums present didactical and pedagogical features that come from the *non-formal* education as well as the *formal* education, presenting as focus methods that validate the learning from *concrete experiences* and the approach of the students with the environment.

### Final Considerations

This project in partnership with the exhibition “Sentir prá Ver” was aimed at giving deafblind people the opportunity to appreciate a work of art, using a guide-interpreter to help a person with deafblindness communicate. By encouraging the deafblind person to

express the “living picture” that represents the work of art, we provided the possibility for the individual to make their own interpretation of the theme “embodying the work by the example.” By visiting this exhibition, the deafblind person could actually be immersed in the work of art from a place of appreciation that enabled their better enjoyment through all the accessible resources of this tactile sensory experience.

To think in a universal format is to think of all, and together we can share art.

**Daniella Forchetti** ([daniforchetti@yahoo.com.br](mailto:daniforchetti@yahoo.com.br)) is founder and consultant of Music and Cultural Accessibility Movement, Sao Paulo Brasil

(Editors note: The editor notes with thanks the assistance of Vula Ikinomidis and Laura Monteiro Ancilotto for their assistance with editing this article)

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### Acquired Deafblindness Network

Liz Duncan  
Email: Liz.Duncan@sense.org.uk  
<http://adbn.deafblindinternational.org>

### CHARGE Network

Andrea Wanka  
Email: aw@andrea-wanka.de  
<http://chargenetwork.deafblindinternational.org>

### Communication Network

Marleen Janssen  
Email: h.j.m.janssen@rug.nl  
<http://communication.deafblindinternational.org>

### European Deafblind Network

Ricard Lopez Manzano  
Email: rlopez@sordoceguera.com  
<http://edbn.deafblindinternational.org>

### Ibero Latin America Network

Vula Ikonomidis  
Email: vula2004@hotmail.com  
<http://iberolatinamerican.deafblindinternational.org>

### Network of the Americas

Marianne Riggio  
Email: Marianne.Riggio@Perkins.org  
<http://americas.deafblindinternational.org>

### Outdoor Network

Joe Gibson  
Email: deafblindoutdoors@gmail.com  
<http://outdoornetwork.deafblindinternational.org>

### Research Network

Prof. Walter Wittich  
Email: walter.wittich@umontreal.ca  
<http://research.deafblindinternational.org>

### Rubella Network

Nigel Turner  
Email: nigel.turner@sense.org.uk  
<http://rubella.deafblindinternational.org>

### Social-Haptic Communication Network

Dr. Riitta Lahtinen & Russ Palmer  
Email: riitta.lahtinen@icloud.com;  
rpalmer2@tiscali.co.uk  
<http://socialhaptic.deafblindinternational.org>

### Tactile Communication Network

Paul Hart  
Email: phart@sensescotland.org.uk  
<http://tcn.deafblindinternational.org>

### Usher Network

Emma Boswell  
Email: Emma.Boswell@sense.org.uk  
Nadja Högner  
Email: nadja.hoegner@hu-berlin.de  
<http://usher.deafblindinternational.org>

### Youth Network

Simon Allison  
Email: simon.allison@sense.org.uk  
<http://dbiyn.deafblindinternational.org>

# CHARGE Network

Andrea Wanka reports:

## DbI CHARGE Network PreConference



European Conference participants and members of the DbI CHARGE Network are invited to join the **2ND PRE-CONFERENCE OF THE DBI CHARGE NETWORK** on September 4, 2017 in advance of the 9th DbI European Conference on Deafblindness. The pre-conference will be held at the Aalborg Kongres & Kultur Center, Aalborg, Denmark, 0800 to 1645.

Three main topics will be presented and discussed in depth during the session:

### THE BODY, COMMUNICATION AND IDENTITY

Presentations will include Fun Chi, Posture and Movement, the role of vision and touch in joint attention, making friends, socialization dyads of older and younger students, self-identity of young adults, and the beginning of a lifeline.

Speakers include Sharon Grassick (Australia), David Brown

(USA), Marga Leefkens-van den Broek (Netherlands), Gail Deuce (UK), Susan Bruce (USA), Lynn Skei (Norway) and Susan Bashinski (USA).

The preconference price is **€58.50** and includes venue entry, refreshments and lunch. The fee is payable by credit card. Registration can be done on the website: <http://dbi2017denmark.com/charge.aspx>

**For further enquiries please contact Andrea Wanka (aw@andrea-wanka.de) or Gail Deuce (gaildeuceconsultancy@gmail.com)**

You are also very welcome to join the CHARGE Network meeting during the conference. The meeting is planned for September 7th, 2017 from 15:30 till 17:00 o'clock.

## Other announcements:

Don't forget the **13th International CHARGE Syndrome Conference: Taking CHARGE in Orlando**, from July 27th until July 30th, 2017 at Rosen Shingle Creek Hotel Orlando, Florida, USA. More information is available at: [www.chargesyndrome.org/for-families/conferences/](http://www.chargesyndrome.org/for-families/conferences/)

On October 14th, 2017, there will be a CHARGE day in the

German Federal County of Baden-Württemberg, featuring Dr. David Brown as a speaker. This will take place at the Stiftung St. Franziskus, Heiligenbronn. You can contact Ann-Katrin Bihler if you would like to have more information ([ann-katrin.bihler@stiftung-st-franziskus.de](mailto:ann-katrin.bihler@stiftung-st-franziskus.de)).

We are very much looking forward to see you in Denmark in September!





# Communication Network

## Marleen Janssen reports:

This past November (2016) during the conference for the 10 years anniversary of the Master Communication and Deafblindness in Groningen, Ton Visser and Inger Rodbroe retired from the Communication Network after more than 25 years. Recently in March we had a meeting with the other members Jacques Souriau, Anne Nafstad, Marlene Daelman, Paul Hart, Flemming Ask Larsen, including me.

There we talked about how to change the format of the DbI Communication Network to develop a larger network of individual members in the way the Board of DbI wishes to see the networks operate. We decided to stop the old network as it previously

operated and suggested that we be open to a large Communication Network with the possibility of subgroups. It was also agreed that I should chair this new Communication Network for the near future.

We are organizing a Communication Network meeting during the upcoming DbI European Conference in Aalborg. During the last half hour of the Network meeting we will discuss this new format. Our idea is to make this a very large network, where nobody is excluded. If people want to make working groups, study groups or research groups within this network that should all be possible. I shall chair this meeting in Aalborg and we'll make an e-mail list of all participants who are

interested, which will be the basis for the new network. The new Communication Network will be open also for people who are not present at the Aalborg Conference.

The old Communication Network group will go on as Study Group on Diversity of Communication and a big deal of their work will be spent on the Master program in Groningen. If future working groups within the Communication Network want to report on their activities in DbI Review I shall coordinate these written reports for the whole network; but of course, the reports can be written by other members. Hope to see you at the Network meeting of the Communication Network in Aalborg!!



**Marleen Janssen** (h.j.m. janssen@rug.nl), Chair Communication Network

# Outdoor Network

## Joe Gibson reports:

This will be a busy summer for the network. Many members are presenting workshops at the DbI European Conference in Denmark in September and there will also be the Network session which will be a chance to meet other members of the group and see some short presentations from three different countries.

Denmark will also host the annual Outdoor Network Week. It will be held in the north of Denmark at

Feriecenter Slettestrand (<http://slettestrand.dk/>) and will run from Monday 18th September until Friday 22nd September. See announcement.

If you wish to join DbI Outdoor Network via either the mailing list or the Facebook Group, (or both) please send a message at the address below.

**Joe Gibson, Coordinator Outdoor Network. Email: [deafblindoutdoors@gmail.com](mailto:deafblindoutdoors@gmail.com)**





We are pleased to announce  
details of this years

## Deafblind International, Outdoor Network week

In 2017 the week will be held in the north of Denmark  
at Feriecenter Slettestrand (<http://slettestrand.dk/>).

The week will run from Monday 18th  
September until Friday 22nd September  
The cost will be around 4400 NOK per person  
(approximately €470 or £405)

During the week you will have  
the chance to try:

- Trekking in the dunes and hills around the center. Accompanied with a local guide that knows a lot about herbs and vegetables growing wild in the surroundings. We shall then use the herbs for cooking.
- Maybe fishing from a boat from a nearby harbor.
- Horsewagon trip in the beautiful area close to the beach.
- Late night swimming in the pool with special aromas and dimmed lights or candlelights.
- Outdoor cooking.
- "Hinderbahn": Helping each other pass the obstacles on the outdoor "obstacle course".

The contact person for the holiday this year is  
Peter Mathiasen ([pema@rn.dk](mailto:pema@rn.dk))

## Research Network

Walter Wittich reports:

The DbI Research Network is moving into its third year of existence, and we continue to grow and expand. As of May 2017, we now have 103 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continue to maintain the Deafblind International Research Network – Facebook Group<sup>1</sup>, currently at 169 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain our Deafblind International Research Network LinkedIn group<sup>2</sup>, currently with 45 members and 15 different conversation streams.

The Action Research Working Group, led by Susan Bruce continues to promote collaborative opportunities, and you can learn more about her efforts on our Research Network web page. Additional initiatives are always welcome, so please get in touch with any of the members of the DbI Research Network, in case you have an idea you would like to share.

Several members of the Research Network are getting ready to present their most recent findings at the 12th International Low Vision Research and Rehabilitation (ISLRR) congress<sup>3</sup> to be held in The Hague, Netherlands, from the 25th to the 29th of June 2017. These two symposia are co-sponsored by Deafblind International, and Walter Wittich will host both the panel on congenital and on acquired deafblindness. We are proud to include the following members of the Research Network as presenters,

<sup>1</sup> <https://www.facebook.com/groups/158743377516989/>

<sup>2</sup> [www.linkedin.com/groups/8339092/](http://www.linkedin.com/groups/8339092/)

<sup>3</sup> [www.islrr.org](http://www.islrr.org)

including Jude Nicholas (Norway), Susan Bruce (MA, USA), Marleen Janssen (Netherlands), Susan Bashinski (MO, USA), Mijkje Worm (Netherlands), Saskia Damen (Netherlands), Bernadette Gavouyere (Quebec, Canada), Karen Keyes (Ontario, Canada), Alana Roy (Australia), Ton Roelofs (Netherlands), and Peter Simcock (United Kingdom). The panel content is as follows:

**Congenital Deafblindness: Current and Future Priorities**

Pediatric vision rehabilitation service delivery is often made complicated by the presence of comorbidities such as hearing loss. Given the low incidence of congenital deafblindness, the number of researchers in this subspecialty is extremely sparse and we are excited to have six specialists in this domain assembled to discuss current issues in congenital deafblindness research and its rehabilitation. This panel was made possible through partial funding by Deafblind International to promote the DbI Research Network (<http://research.deafblindinternational.org/>). Given the profound impact of early sensory loss on human development, the complexity of care and the challenge of communication are at the core of the panel topics. The panel will be opened by Jude Nicholas (Norway), describing the difficulties encountered in “Understanding the complexity of congenital deafblindness”. Since service delivery with this vulnerable population should be based on evidence-based practice, Susan Bruce (USA) will then examine “Effective Instruction of Students who are Deafblind: What is the State of Our Evidence?”. One major preoccupation when working with deafblind children is communication. Therefore, Marleen Janssen (Netherlands)

will present recent development on “Intersubjective communication: A model for guiding high quality communication interventions in people with deafblindness”, with specific implications on service delivery. Thereafter, Susan Bashinski (USA) will be “Identifying Effective Strategies for Teaching Communication, Language and Literacy Skills, with Learners with Congenital Deafblindness” which ties nicely into the continuing priority of communication research, leading to the presentation by Mijkje Worm (Netherlands), discussing “Communicative engagement of a person with congenital deafblindness in narrative and multiparty conversational practices”. The theme of communication is then concluding with the final presentation by Sakia Damen (Netherlands), who will present approaches of “Scaffolding Communication in People with Congenital Deafblindness: An Analysis of Sequential Interaction Patterns”.

**Acquired Deafblindness: Rehabilitation Challenges with Older Adults**

With the changing demographic profiles in many countries around the globe, low vision rehabilitation has seen an increase in more complex cases, whereby many working-age and older adults with visual impairment also present with comorbidities such as age-related or noise-induced hearing loss. The rehabilitation of these adult clients requires quite different approaches than the traditionally more established congenitally deafblind rehabilitation clientele. The upsurge in this population has increased research efforts, some of which will be presented by members of this international panel. Bernadette Gavouyère (Canada) will set the initial tone by presenting “How to develop best practices in rehabilitation: The

birth of a community of practice in deafblindness”, a presentation that will introduce a new tool towards improved evidence-based practice. She will be followed by Karen Keyes (Canada) who will provide a life-span perspective, examining “Intervenor services for adults with congenital deafblindness in Ontario, Canada – how far have we come?”. “The importance of combined visual and auditory functions for the visual rehabilitation of clients with dual sensory loss” will be discussed in a presentation by Ton Roelofs (Netherlands), which then leads into a presentation by Peter Simcock (UK) who will provide a global view of “The UN Principles on Aging – A perspective on Deafblind Seniors”, which will specifically examine aging with either congenital or acquired combined vision and hearing loss. Finally, Walter Wittich (Canada) will conclude the session with an overview of three studies that examine “The stigma of assistive devices as experienced by older adults with combined vision and hearing loss”. Overall, the purpose of the session is to give an overview of key current topics in the domain of deafblindness, as they relate to aging across the lifespan.

Partial Funding for this symposium was provided by Deafblind International to promote the DbI Research Network (<http://research.deafblindinternational.org/>)

If you have any ideas for us, or requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page and contact us with your interests and thoughts.



**Walter Wittich**  
([walter.wittich@umontreal.ca](mailto:walter.wittich@umontreal.ca))  
on behalf of the  
DbI Research  
Network Team

## Harnessing the power of collaboration in sensory loss research

By Christine Lehane



Collaboration between departments, both nationally and internationally, has the potential to accelerate progress within a research field and enhance the quality of published work. In 2015, during the 16th Deafblind International (DbI) world conference, cross-departmental collaboration was established as a goal with the formation of the DbI Research Network. Since its launch, researchers at the University of Copenhagen, Denmark (KU)<sup>1</sup> and the University of Montreal, Canada (UdeM)<sup>2</sup> have collaborated to advance one underdeveloped subfield within sensory loss research—intimate relationships. With the publication of their pilot study in 2011, Dr. Walter Wittich and colleagues at the School of Optometry, UdeM called attention to the need for researchers in this field to not only consider the impact of sensory loss on diagnosed individuals but also their spouses. In a similar vein, Christine Lehane and Dr. Jesper Dammeyer of the Department of Psychology, KU were interested in understanding whether sensory loss impacts the lives of couples and how couples cope with the challenges they face when living with hearing, vision, or dual-sensory loss. In order to develop a study that would be interesting from both a theoretical and applied perspective, Dr. Wittich was invited to join the researchers at KU in the development of what is now referred to as the International Study of Support and Sensory Loss (Project ISSSL)<sup>3</sup>.

Project ISSSL was launched in June 2016 and is due to end in August 2017. In working together, the

research team designed a project referred to by participating couples as “a thorough piece of research” and managed to recruit what has been referred to by journal reviewers as “a very strong sample”. Since the beginning of their collaboration, the team have accomplished much more than is typically expected of a single project. For instance, to date, the project has been presented to research and rehabilitation audiences in Denmark, Sweden, Canada, and the USA; two articles have been accepted/published, and several others are under review or in preparation; the team’s research has also received media attention; and, researchers from other institutions have been in contact to initiate further collaboration in future projects. The primary message demonstrated by the recent success of this team is that collaboration across departments can be immensely beneficial, affording the identification of gaps in current knowledge and the means to address them. As with all new research fields, research in sensory loss still contains a number of unanswered theoretical and clinical questions – a challenge that could be minimised by cross-departmental collaboration.

**Researchers interested in learning more about the DBI Research Network can contact Dr. Walter Wittich, (Inaugural Chair; Email: [walter.wittich@umontreal.ca](mailto:walter.wittich@umontreal.ca)), or Christine Lehane ([christine.lehane@psy.ku.dk](mailto:christine.lehane@psy.ku.dk)) or can visit the network website: <http://research.deafblindinternational.org>**

## Usher Network

Emma Boswell reports:

**Hope you are having a fantastic start to the Summer?**

Are you keen to learn more about Usher Syndrome? Do you want to meet other professionals working in the Usher field? Do you want to meet people with Usher and find out about their achievements, challenges and what kind of support they receive? Then you have certainly come to the right page!

To find out more why not come and book a place to attend the Usher Network Pre-conference on 3rd and 4th September? Please see the link; <http://usher.deafblindinternational.org/> <https://www.eventbrite.co.uk/e/dbi-deafblind-international-usher-network-pre-conference-september-2017-registration-33002989831> Please look at Deafblind International Website (under the Networks sections for Usher Network)

We have been busy preparing the International Usher Network Pre-conference, on 3rd and 4th September 2017. The committee members have been fantastic in putting together an exciting and interesting programme with a variety of speakers. We are delighted to have a diverse range of speakers, including a professional physiotherapist who has Usher. We have made sure that the programme covers different topics (including a family panel) so we can see different perspectives from people and professionals alike, at home and on an international basis within the Usher community – which is very close to my heart...

<sup>1</sup> [www.ku.dk/english](http://www.ku.dk/english)

<sup>2</sup> [www.umontreal.ca/en](http://www.umontreal.ca/en)

<sup>3</sup> [psychology.ku.dk/research/research\\_groups/pcare/research/issl/](http://psychology.ku.dk/research/research_groups/pcare/research/issl/)

As some of you may already know I have Usher syndrome type 1 and work for the fabulous Sense UK, a Deafblind charity. Due to our government's cuts, like many other countries, we are facing enormous challenges. I am fighting to get an international budget to support my needs so I can access the pre-conference. In the UK disabled people can apply for an Access to Work (AtW) grant, from the UK government, which can provide practical and financial support in the workplace. Unfortunately, they have refused to pay for my support to access international events – which is the first time this has happened in my professional life. Not only am I facing challenges with my AtW budget, I am also facing a daunting assessment by a PIP assessor with regards to my everyday life. PIP – Personal Independence Payment, is financial support for people 16–64 years with a disability or chronic condition. People with Usher are likely to develop mental health issues due to the stressful circumstances we have to deal with in the fight for our rights... is this the same in your country? What are professionals doing to support the Usher community through these difficult times? How do people with Usher navigate the many barriers they face? We'd love to hear from you, and what better way to do this than in the picturesque surroundings of Aalborg, with like-minded people?

Please come and join us at the pre-conference.

We look forward to seeing you all in Denmark... or Glæd dig til at se dig der!

Tak!



**Emma Boswell**  
(emma.boswell@sense.org),  
Usher Network  
Chaireww



## DbI Pre-conference on Usher Syndrome

Aalborg Congress & Culture Center,  
Aalborg, Denmark

3RD & 4TH SEPTEMBER, 2017

**Are you keen to learn more about Usher syndrome?**

**Do you want to share your professional experiences in this field?**

**Do you want to learn more from people with Usher about their own personal experiences, challenges and achievements?**

If so, then join us at the International Pre-Conference for a fascinating programme of Usher events covering psychology, employment and social fields, as well as a 'family panel'. There will be speakers from Denmark, USA, Germany, Australia and the UK, together with people from all areas of the Usher community, including professionals, Usher people & their families.

Throughout the two days, there will be fresh coffee & tea and a buffet lunch. Not to mention legendary Danish pastries!

There are three categories of fees, professionals, Usher (& family members) and communication support.

**The fees are:**

- Professionals – €216
- Support workers / interpreters – €119
- Usher / Family – €90

**TO REGISTER, please go to:**

<https://www.eventbrite.co.uk/e/dbi-deafblind-international-usher-network-pre-conference-september-2017-registration-33002989831>

**For more information on the conference please go to: <http://usher.deafblindinternational.org>**

**For more information about Denmark please go to: <http://dbi2017denmark.com/dbi-usher.aspx>**





## PRE – CONFERENCE EVENT

### Deafblind International Youth Network (DbIYN)

In the beautiful Danish City of Aalborg

- Two nights accommodation including breakfast at the Hotel Aalborg, situated in the centre of Aalborg
- Full programme of activities including Aalborg Zoo, Lindholm Viking Village and Bowling at the Seaport Centre
- Opportunities to make friends with other Deafblind young people through our evening of interactive workshops
- Event dates are prior to the 9th DbI European conference

*“The DbI youth network activity at Disneyland Paris was an experience I will always remember. I made so many new friends from all over the world.” – GRACE*

*“It is important to have friends who are deafblind like myself, we share experiences in the youth network together and we can reflect with smiles and laughter.” – SACHA*

**EVENT START 3pm Saturday Sept 2nd**

**EVENT FINISH 3pm Monday Sept 4th**

Total Cost (not including travel to and from Aalborg)  
£250 British Sterling – Payable in advance

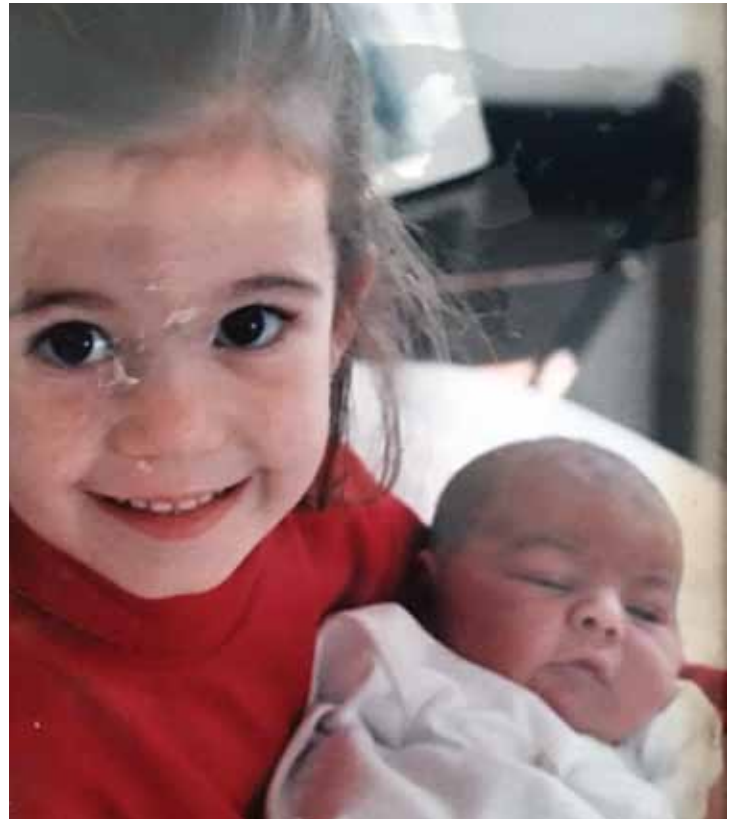
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# From Mylar Hats to the Classroom: A Personal Journey

Paige Furbush

When I was five years old, my sister Claire was born with Agenesis of the Corpus Callosum<sup>1</sup>, resulting in a diagnosis of Aicardi's syndrome<sup>2</sup> and deafblindness. She had little to no control over her body, and as an infant, was incredibly withdrawn from her environment. I was so young, but remember being very committed to studying her every movement, expression, and reaction to various environmental stimuli. All I wanted was to be able to understand her and, maybe even most of all, to know that my baby sister liked me. It became clear to me that her communication wouldn't be like any other baby's. When she enjoyed an activity and wanted it to continue, she didn't laugh and look expectantly at you like a typical baby would. Instead, I noticed that she would slowly open her mouth into her own version of a smile and tilt her head slightly up and to the right. When she was unhappy or overwhelmed, she would close her eyes and turn her head all the way to the left. She was nothing like me, but I was allowing

myself to become more like her by immersing myself in her world. The vision specialist who provided in-home services to my sister through Early Intervention told us that we could try using toys that were shiny and reflective to play with Claire and stimulate her vision. Mylar worked especially well; when Claire saw anything mylar, her state of alertness would instantly change. She was aware of her surroundings and was more willing to reach out and engage. I decided to make a hat out of mylar in hopes that it would allow Claire to see my face. It worked! When I wore the hat, she would look right at me and smile. I will never forget how I felt when I realized that I was finally playing with my baby sister. This led to a stronger connection than I could have ever hoped as I learned how to communicate with her, how to make her laugh, and how to soothe her. Claire passed away right before she was about to start kindergarten, but what I learned from her has had an incredible impact on my current professional practice as an early childhood special educator.



Paige and Sister Claire first day home from hospital

*“Through my experience with my sister, my perspective on what is considered ‘normal’ shifted at a very young age.”*

<sup>1</sup> Agenesis of the corpus callosum (ACC) is a rare birth defect (congenital disorder) in which there is a complete or partial absence of the corpus callosum. It occurs when the corpus callosum, the band of white matter connecting the two hemispheres in the brain, fails to develop normally, typically during pregnancy.

Agenesis of the corpus callosum ([https://en.wikipedia.org/wiki/Agenesis\\_of\\_the\\_corpus\\_callosum](https://en.wikipedia.org/wiki/Agenesis_of_the_corpus_callosum))

<sup>2</sup> <https://aicardisyndrome.foundation.org/aicardi-syndrome/>

Aicardi syndrome is a rare neurologic disorder first described by the French neurologist, Dr. Jean Aicardi, in 1965. It occurs almost exclusively in females (46,XX)

Through my experience with my sister, my perspective on what is considered 'normal' shifted at a very young age. At the beginning of each new school year, I didn't automatically assume that my classmates would verbally state their names as we went around the room making first day introductions. I had no expectations regarding how my classmates might interact with me socially, or how they might express the wide range of emotions a child feels in a day. To me, it was just as normal for children to simply tilt their head to the side and make themselves fall asleep to indicate that they didn't want to do something as it was for someone to politely say, "No thank you." Having fun while playing with another child didn't have to involve an elaborate, imaginary scenario involving me as the beautiful princess with my playmates taking on the roles of the ugly stepsisters (though I'm told this was my preferred arrangement on the preschool playground.) I could just as easily play a simple game of peek-a-boo or repeatedly throw balls up in the air while sitting stationary in a ball pit. To me, these were all just different ways to play and develop friendships. One did not feel more valuable or desirable than the other simply because of the presence of unrestricted mobility and verbal language. A conversation of shared movements, reciprocal play with objects, vocalizations, and facial expressions was just as meaningful to me as one with words.

It wasn't until I got older that I realized most people did not share my views and

understanding of people with deafblindness or other significant disabilities. We are conditioned to develop an idea of what is 'normal'. A 'normal' person walks on two feet, can see and hear what's going on around them, and carries on polite conversations with others through verbal language. When many people encounter someone who doesn't fall within their expectation of 'normal', they might feel uncomfortable or perhaps afraid because they don't know how to interact with this person. Often, they feel sympathy for this person. They may think that, because this person's daily experiences aren't the same as theirs, they don't have a high quality of life. After my sister passed away, multiple people said that perhaps this was a blessing in disguise, as she would have spent her life confined to a wheelchair and would have never led a 'meaningful life' or become a 'contributing member of society'. I quickly realized that others' expectations of someone who is deafblind is that they are somehow 'less than' and impossible to connect with. It was not a difficult decision for me to make to pursue an education and career in early childhood special education and later,

a specialization in deafblind education. I wanted to not only serve these children and their families, but also challenge others' notion of 'normal' so we can show the world just how meaningful it is to have a Claire in your life.

Children who are deafblind are often referred to as one of the most challenging student populations to work with because their disabilities tend to be some of the most severe. Most people hear 'deafblind' and can barely wrap their head around the classification. "How do they communicate?" "How can they possibly learn?" "There's no way they can function in a regular classroom, right?" These are all questions I have heard quite frequently, and I believe one of the most valuable qualities I bring to this field is a different perspective. To me, it is not just about adapting my instruction and classroom environment to accommodate children who are deafblind. I see these children differently and am able to connect with each child in a way that lets them take the lead and teach *me* how to communicate with and get to know *them*.

I have only been teaching for two years, but have already been presented with the most rewarding challenge:

***“I wanted to not only serve these children and their families, but also challenge others' notion of 'normal' so we can show the world just how meaningful it is to have a Claire in your life.”***





Paige and student Maddie

teaching two preschool students who are deafblind in an inclusive setting. Actually working among other professionals in the field of special education now, I can see why my mother came home from each one of my sister's IEP meetings in tears. Even the professionals who are responsible for teaching these children and advocating for their families act as if they are 'too disabled' to learn and make progress. One of my students was described to me as having no attention span, being self-injurious and unable to functionally use toys. Other adults who worked with this child expressed serious concern over the student 'putting everything in her mouth'. Typically, mouthing is categorized as infantile behavior, but what about the child who is deafblind and must experience his or her environment primarily

through the sense of touch? If this is the child's most reliable way to take in and process information about an object, who am I to say this is unacceptable?

After careful observation, I discovered that one of my children responds well to rough textures. As she explored a small piece of rough Velcro, I timed how long she interacted with the material. She sat in a chair independently for five minutes mouthing the Velcro and touching it to her face. Using this information, I attached strips of rough Velcro to a variety of developmentally appropriate toys. In a week and a half, she had far exceeded her IEP goal to simply hold developmentally appropriate toys for 10 seconds. From here, I was able to accurately assess whether or not she had developed cause and effect and object permanence because the

items used for the assessment were adapted to ensure her ability to focus and stay motivated to engage with me.

Since highly preferred items were now easily identified, I was able to follow the student's lead and engage with her in activities that she chose and initiated. I would imitate her actions (sometimes it was as simple as her climbing onto a table next to a window and hitting the window) and we were able to engage in a reciprocal turn-taking game. From there, I would add sounds and was thus able to assess her ability to imitate, and after a routine was established, pause to give her a chance to request 'more' in her own way (patting my hands in this scenario, or kicking her legs, making eye contact and making a high-pitched noise to signal that she wanted me to continue spinning her on my desk chair). In a short (and

## From Mylar Hats to the Classroom

enjoyable) time, I was able to truly understand my student's present level of functioning in order to best meet her needs.

Another idea people seem baffled by is that I teach students who are deafblind in an inclusive setting. This means that my classes are made up of typically developing children, as well as children with other disabilities who are on IEPs. They seem doubtful of the fact that I am able to adequately meet each student's unique needs, especially those who have more severe disabilities. They want to know if it's *really* possible for a 5-year-old who can read sight words to engage in and enjoy the same activity as a 4-year-old who is deafblind and still working on mastering the concept of object permanence. I truly believe that yes, this is absolutely possible; as long as you look at the outcome from a different perspective.

Children are unique in how they approach and engage in any given activity and each child may have a unique outcome from participation

in the activity. One child may gain a more thorough understanding of different communication styles. The other child may learn that the world beyond their hands may not be as scary as they think and that reaching out and exploring that world can lead to meaningful interactions and the development of relationships with other people. One of my students who is deafblind spent the first 4 months in my classroom sitting in our enclosed book area, refusing to leave what she felt was a safe space. When another child came into her space, she instinctually pushed them out of her way. I taught her classmates to approach her carefully from the front and make their presence known by waving and saying the child's name. After awhile, they noticed that this student loved to clap, so they would greet her by clapping. This evolved into the children playing simple games like pat-a-cake with each other and holding hands when they walk down the hall. My student who is deafblind is no longer fearful of her peers and this has allowed her to venture out into the classroom and explore the rest of her environment. Her development across developmental domains has absolutely exploded over the past few months. She participates in all classroom activities alongside her peers and her classmates are regularly fighting over who gets to help feed her and who gets to take her for a walk in the hall with her new pre-cane device. Her peers are no longer wary of the child's differences either. They actually pride themselves in being able

to tell *me* what their friend needs based on the way she is clapping or what vocalizations she makes. Last week, they decided that I needed to add 'clapping' as a choice to our morning greeting board, alongside high fives, waving, and fist bumps, because that's how their friend says hi to them. At age 4, my preschoolers have a better appreciation of the value of diversity than many adults. They truly know that different is just different; never less.

I sincerely hope that, by educating other professionals, community members, and my students' parents to help them better understand and advocate for their children and their needs can help to change the current narrative for children who are deafblind. Without widespread understanding of how to reach these unique children, we will continue to see professionals and community members turn their backs on them simply because they feel unequipped to 'handle' them. My desire to understand children who are deafblind is just as strong now, at age 26, as it was when I was five years old, making hats out of mylar in an attempt to get my sister to smile.

**Paige Furbush (paige.furbush@jordandistrict.org) is a teacher in an inclusive special education preschool classroom in the Jordan School District in Salt Lake City, Utah. She received her Bachelor's degree in Early Childhood Special Education from the University of Utah and is completing her Master's Degree in Deafblind Education at the University of Utah, located in Salt Lake City, Utah.**



Paige with student Brooklyn

# Developing awareness of deafblindness in health and social care provision for older people

Jonathan Ling<sup>1</sup>, Pat Watson<sup>2</sup>, David Sutton<sup>3</sup> and Bernard Quinn<sup>4</sup>

## INTRODUCTION

**D**eafblindness is most prevalent in later life, with 87% of those with more severe dual sensory impairment aged 60 or over (Robertson & Emerson, 2010). The difficulties with communication and mobility caused by deafblindness are particularly profound for those in later life, where acquired communication disorders often coexist with difficulties in independent living, access to support and social isolation (Pavey, et al., 2009). Social isolation, which is a negative outcome in its own right, also means that people with dual sensory impairment may not be known to those health and social care services which could provide support for them. When deafblindness is under-recorded, it is likely that there will also be under-provision of appropriate services for people who are deafblind. Therefore, identifying people who are deafblind within the community is crucial to both the delivery of necessary support and the appropriate assessment of the level of support needed across a community.

### *Recognising and assessing deafblindness*

Recognising deafblindness for service providers such as social and health services and care homes can be difficult. Frontline staff require training to be aware of dual sensory impairment and how this affects the provision of advice and signposting to services. While health and service providers may be aware of their duty to identify, contact and keep a record of individuals with deafblindness, there is likely to be less awareness of the impact of other disabilities in masking dual sensory impairment, something which may be more critical to older people who may have other physical or mental impairments due to a stroke, dementia, Parkinson's,

learning difficulties, which could reduce the likelihood of a diagnosis of deafblindness.

Local authorities in the UK have a duty to assess any adult who appears to have a need for social care or support, such as people who are deafblind. This issue has important implications for training – not only for those staff involved in assessment, but also for those who have a client-facing role who would be able to make an initial basic assessment of deafblindness and then refer for appropriate specialist assessment. Knowledge of deafblindness is needed to correctly assess individuals, and social care professionals with such specialist knowledge are more likely to identify the impacts of dual sensory loss (Sense, 2013).

### *In Good Hands*

Preventative services delivering social care to support people to live independently can help reduce social isolation and improve quality of life. Furthermore, such provision can decrease the burden on the existing health and social care system (Goodwin et al., 2012). In Good Hands (Scene, 2013) is a project run by Scene Enterprises and funded by the UK Big Lottery Fund<sup>5</sup> to both build capacity of organisations and services to support people with deafblindness, and to increase the number of older people identified with age-acquired deafblindness.

In Good Hands is a programme of awareness raising, training, qualifications and opportunities devised



Jonathan Ling



Pat Watson



David Sutton



Bernard Quinn

<sup>1</sup> Email: ; University of Sunderland (<https://www.sunderland.ac.uk>)

<sup>2</sup> Email: Teesside University (<https://www.tees.ac.uk>)

<sup>3</sup> Email: Scene Community Interest Company ([www.sceneenterprises.org.uk](http://www.sceneenterprises.org.uk))

<sup>4</sup> Email: Scene Community Interest Company

<sup>5</sup> [www.biglotteryfund.org.uk](http://www.biglotteryfund.org.uk)

and developed by Scene Enterprises CIC and utilised by In Good Hands to support older people with deafblindness. In Good Hands also delivers support and training around age-acquired communication disorders to local authorities, care homes and other stakeholders.

The intended outcomes of In Good Hands are:

- Effective communication between volunteers, care givers and older people who are deafblind
- Improved mental health and physical wellbeing of older people who are deafblind
- Increased confidence and knowledge of how to access services and specialist equipment available to support people who are deafblind
- Support older deafblind people to maintain their independence and to re-engage in social and community activities.

These outcomes were approached through raising awareness of deafblind issues and providing specialist training to health and social care staff, volunteers and families to ensure they were better equipped to identify, assess and support older people who are deafblind and ensuring that community organisations with volunteers are better placed to reduce the social isolation often faced by people who are deafblind.

### METHODS

#### *Design*

An action research approach (Minkler & Wallerstein, 2008) was chosen as it offered an evaluation framework which emphasised the need to work closely with those developing and delivering In Good Hands as well as the service users who are likely to benefit from the project. As a result, a range of data were collected from multiple sources, including dialogue with the project team in order to understand and identify new developments, a review of existing literature, training for volunteers to take an active research role, Interviews with people who have completed one or more of the training packages provided to inform content of questionnaire, an online questionnaire for people who have completed training and interviews with deafblind people.

#### *Participants*

A total of 16 people were interviewed about their experiences and impact of the training. A further 17 interviews were carried

out with people who are deafblind. Although in this paper we focus on the impact of the training on policy and practice. We also analysed monitoring data to find out how many people were trained, as well as the sector they came from.

#### *Ethics*

Ethical approval for this evaluation was provided by the Teesside University School of Health & Social Care<sup>6</sup> Research Ethics and Governance Committee prior to the start of this evaluation.

#### *Data Analysis*

A thematic analysis was conducted (Braun & Clarke 2006) using NVivo10, a qualitative data analysis programme, to manage the data and aid analysis.

### RESULTS

#### *Uptake of training*

Training was provided free of charge and was open to all sectors that had some contact with This includes the public, voluntary and independent care sector, voluntary organisations and individuals e.g. families and voluntary carers. All 12 local authorities in the North East of England participated in the training.

Monitoring data collected by IGH shows that over an 18-month period 1443 people successfully completed some form of accredited training through the programme. This included 355 social workers trained as specialist deafblind assessors. Some people completed more than one course. Just over



<sup>6</sup> [tees.ac.uk/health&socialcare/](http://tees.ac.uk/health&socialcare/)

half (52%) of completions were for the foundation course, with the remainder evenly split between specialist deafblind assessor, communicator guide and acquired communication disorder training. This was expected given the aim of raising awareness and this also provided a basis for people to move on to the other more advanced courses.

A further breakdown of course by sector shows that the voluntary sector (509 people completing training), independent (245) and public sectors (633) engaged well with the training, along with 56 who were not affiliated with any organisation. The voluntary and independent sectors (primarily social housing organisations and the care sector) engaged well with the foundation training. The majority of public sector involvement was around the Specialist Deafblind Assessor Training.

### INTERVIEWS

#### *Awareness raising*

Participants reported that their awareness of deafblindness and its effects on people had increased as a direct result of the training. The foundation level training provided good insight on identifying signs that a person has a dual sensory impairment. The training had an impact from raised awareness at operational and individual levels, with some changes beginning to be instituted at strategic/policy level.

Individuals completing the training reported benefits of increased awareness in both their work and personal lives.

*I learned so much that I hadn't even thought of before and feel more able to help people who can't see and are deaf.*

*It has even made a difference for me with my family. I find I am passing on information to other members of my family.*

There was a general view that the training raised awareness of deafblindness, provided reassurance and reinforced prior learning. Given the numbers who have completed the training and the geographical spread, this was a good step towards informing support and services further in the future.

#### *Improving confidence, knowledge and understanding*

Participants reported that prior to the training, they felt providing care and support for people who are deafblind could be complex and that they lacked the confidence to do this. However, participants felt that the training increased their confidence in engaging, communicating and supporting people who are deafblind.

*Some of our staff who haven't done the training panic if they come up against someone who is deaf and blind. I would say that all of the staff who have done the training are a lot more confident to be able to support them much better.*

The majority of interviewees reported improved confidence which helped them to work more effectively with people

who are deafblind. They reported a link between increased knowledge and understanding which resulted in increased awareness and confidence but also the ability to be more effective in their work with people who are deafblind.

*The training gave most of our care home workers a better insight into how day-to-day life was for one particular client. It helped us to be able to focus better on his needs.*

#### *Improved communication skills*

Communication was identified by participants as a major problem when working with people who are deaf and/or blind, and they reported communication was more problematic for people who are deafblind. For those who are providing care, adequate communication with people who are deafblind is essential if their needs are to be met. Communication skills were covered to varying degrees within each of the courses but responses focused on personal development and improved communication with clients:

*Knowing even a little bit about talking to them [people who are deafblind] properly has made a difference to me.*

Participants also reported using the skills learned to communicate with clients:

*One lady I work with, I do finger spelling [Deafblind Manual] with her. I showed her how it works and she*

*does it back to me. We are still learning and I've got to do it slowly because she struggles with it a bit but it's working. She can now tell me what it is she wants.*

The communication elements of the training were viewed very positively. The practical elements also helped in terms of putting learning into practice.

### **Changes in working practices**

Those who had been through training reported changing their working practices, primarily in relation to improved ways of communicating, assessing needs and supporting clients. Training was reported by many as leading to changes in their working practices.

At an individual level, people recognised the need to change the way they work with some clients in order to better meet their needs. Comments included:

*It [the training] really makes you think a bit more. I used to put their plate of food down without actually telling them where it is or what it is. Now I go in and say you've got this and then tell them whereabouts on their plate it is. I just hadn't realised what I was doing was so clearly wrong.*

Changes in practice were also reported at an organisational level in terms of checking whether people who are deafblind are present in groups, making support aids such as magnifiers and plate guards more widely available and ensuring hearing aids are well maintained. Some

are in the early stages but serve to highlight the potential impacts the IGH training can have on organisations working with and/or supporting older people meaning those with a high likelihood to include older people with age related dual sensory impairment or loss. These changes are unlikely to have happened without their participating in the training and that these changes do ultimately impact on the quality of service client receive.

### **Organisational changes**

Training affected operational working within organisations. For example, a voluntary organisation that had adopted a telephone contact system for all referrals recognised this would not work for people who are deafblind and offered face-to-face contact to clients. Other organisations committed to getting as many of their staff trained as is possible and where possible, to cascade training down to all staff to facilitate changes in practice. One participant stated:

*Quite a few of us did the training and then we fed that down to all of the leads across the area so every centre had a lead. Then each of the leads arranged meetings with their staff to disseminate the training [...] especially the practical exercises.*

There is some evidence to suggest that the learning and tools available within the training resulted in some changes to handbooks and care planning:

*We have made some amendments to our handbooks and added some questions to our assessments to make sure we find out if a person has hearing and sight problems. Now all the staff are doing this whether they have done the training or not.*

As a result of the training, a voluntary sector organisation recognised that 'touch' is a key aspect of communication for people who are deafblind and so amended its 'No Touch' policy so that those with hearing and sight loss may consent to include touch as a communication aid providing it is appropriate and culturally acceptable. Another organisation providing support to elderly and vulnerable adults ensure they identify people with hearing and/or sight problems seat them close to the group facilitator.

### **Improved services to clients**

Overall, participants felt that training had resulted in improved services to clients. Those who had completed training reported making changes to their everyday practice to improve their communication with clients, such as 'letting them know I have arrived by touching their shoulder', explaining what is on their plate and where it is placed and 'writing notes in very large bold print'. Such changes contributed to improving the quality of life of clients.

Many participants reported that the training sessions provided an opportunity for them to meet others working with these clients, learn from each other and better



Staff Training session

understand about other services available. Examples are beginning to emerge of some partnership working as a result of these developing networks. The awareness of other available services and useful equipment has also resulted in referrals for new services being made and the use of additional aids to support those with a sensory impairment.

Access to services such as hearing aid maintenance resulted in improved hearing for some people. For many elderly people with hearing aids, maintenance can be a problem as batteries and tubes need changing regularly. Finding there are services available to do this resulted in fewer problems with hearing aids, fewer visits to audiology departments for repairs and reduced frustration from service providers and clients alike:

*It makes a real difference to me when my hearing aid is working properly. It opens everything up for me.*

Much of the training was aimed at improving support for clients. Improved communication skills and relevant services and equipment have a role in clients retaining their independence. Those living in residential care were keen to maintain some independence. One care home resident stated:

*I like it here and they do look after me well but I like to be able to do things on my own. Now my hearing aid is working properly, I can join in some of the things they do here, talk to my family on the phone and get on the bus and pop into town if I want to and I really love that feeling.*

While clients may not realise that improvements in their care or services are linked to the training, they did recognise changes in practice and reflected on the benefits. People who completed the training continue to confirm that such improvements are

the result of the training and unlikely to have occurred without it.

***Increase in numbers of people who are deafblind identified and registered***

There was evidence that organisations were identifying increased numbers of clients who are deafblind. There was a perception that as staff begin to know what to look for, they were more likely to identify deafblindness. Dual sensory awareness and communication skills were embedded in a range of workshops aimed at older people including healthy nutrition, good hydration, money management and wellbeing and safeguarding workshops. 'Talk & Try' events were designed as a way of identifying elderly people with sight and hearing problems and providing support, through advice/information, referrals to relevant services or an opportunity to test equipment. These events were positively viewed by those who attended.

### DISCUSSION

The In Good Hands project's key aims were to raise the profile of dual sensory impairment and provide training to improve the skills of people providing care and support to older people. The widespread uptake of this project across sectors indicates the need for dual sensory impairment training. Prior to the project, such training was not readily available. The practical nature of much of the training promoted identification and communication skills, and helped participants to see clearly how to put that learning into practice.

IGH provided new skills to the health and social care workforce to facilitate the identification of deafblind people. Existing literature is clear that while the numbers

of people who are deafblind are increasing they do not truly reflect the full extent of the problem which means many do not receive the services they need. Raising awareness and improving communication are important steps in supporting those who are deafblind, and this work is starting to influence policy making at a local level. Training was cascaded to other staff and practices were changed at an operational level by staff in client-facing roles.

The In Good Hands project has also led to policy change as a result of the raised awareness and better understanding of the issues of communicating with people with dual sensory impairment, such as reconsidering 'no touch' policies and having face-to-

face meetings. Changes to policy, even at organisational level do not happen quickly. The fact that these changes have been made in such a short time indicates that the training has been beneficial and raised institutional, as well as individual, awareness of deafblindness.

### CONCLUSION

Older people who are deafblind are likely to be missed by providers of health and social care. This project has demonstrated that delivering training to frontline care staff can lead to real gains in terms of both the support and the identification of people who are deafblind.

**For more information, contact Jonathan Ling ([jonathan.ling@sunderland.ac.uk](mailto:jonathan.ling@sunderland.ac.uk))**

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## Welcome to 9th DbI European Conference

**Aalborg, Denmark – September 5–8, 2017**

**We are pleased to host the 9th DbI European Conference on Deafblindness in Aalborg, Denmark.**

The theme of this conference is **social connectedness**, about how people come together and interact. We hope you will take this opportunity as professionals, families and people with deafblindness to come together and meet at the conference in Aalborg, Denmark.

**The conference offers many different platforms for sharing knowledge and networking:**

- Plenary sessions with keynote speakers and personal stories
- A wide variety of workshops
- Poster presentations
- Research symposium with an insight to the latest research
- The great debate – about the merging between ethics and economy
- Visit at Center for Deafblindness and Hearing Loss
- Network meetings
- Several pre-conferences and activities ahead of the conference:
  - Usher – preconference
  - CHARGE – preconference
  - Nordic Day
  - Youth network activities.

The conference registration will be re-opened for late registrations until August 20, 2017.

**Please visit the conference website: [www.dbi2017denmark.com](http://www.dbi2017denmark.com) and Facebook: [dbi2017denmark](https://www.facebook.com/dbi2017denmark)**

## Welcome to Denmark in September

**A**s hosts for the ninth European Conference on Deafblindness, we warmly welcome you to Aalborg, Denmark. Aalborg is the biggest city in the North Denmark Region and location for more than 60 years of the Centre for Deafblindness and Hearing Loss (CDH<sup>1</sup>).

Denmark is a welfare state, which means that childcare, education, healthcare, infrastructure, art and culture, libraries, social assistance and assistance to people with disabilities are a public responsibility financed by the country's tax system. The average income tax rate of individuals in the country is around 45–50%. Regardless of personal wealth or private insurances, citizens of Denmark have equal right to healthcare and equal access to education, protection and housing for the aged.

According to Danish law on social service, people with deafblindness are entitled to receive help, to enter into society on equal terms as everybody else. While Denmark signed the *UN Convention on Rights of Persons with Disabilities*<sup>2</sup> in 2008, it was not until 2014 that Denmark signed *the Additional Protocol*. The Additional Protocol gives people the right to complain if their rights are violated.

The Danish deafblind organizations work very close

*...continued*

<sup>1</sup> The Centre for Deafblindness and Hearing Loss ([www.dbc.rn.dk](http://www.dbc.rn.dk)) is a small corporate member of DbI

<sup>2</sup> <https://www.un.org/.../disabilities/convention-on-the-rights-of-persons-with-disabilitie..>

## Conferences

together with the Nordic Center<sup>3</sup> and our Nordic Colleagues. Nordic cooperation is necessary, as deafblindness is too complex for each of the Nordic countries to develop the knowledge about deafblindness alone.

As a member of the Nordic cooperation, we use the Nordic definition on deafblindness of 2016 as follows:

*Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.*

*To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation and the ability to move around freely and safely.*

*To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important.*

The Nordic Definition consider deafblindness as a functional and dialogical disability, which means the disability links to the person's opportunities for participating in society.

CDH provides a complete nationwide program for children with acquired deafblindness, persons with congenital deafblindness and people with hearing loss, including the private and professional networks connected with each of them. CDH has a sustainable cooperation with our sister organization the Centre for Deaf or CFD<sup>4</sup>. CFD is the largest provider in Denmark of services for deaf, deafblind and hearing impaired people (including persons using Cochlear Implants).

The National Board on Social Services<sup>5</sup> coordinates the Danish advisory service for people with deafblindness. CDH and CFD conducts the nationwide counselling based on the current life situation for almost 1000

children, young people, adults and elderly people, and their relatives. New housing, new jobs, changes in life or health, new technological possibilities, new staff are just some of the many challenges that persons with deafblindness meet in a changeable world and which necessitate ongoing guidance.

As the municipalities are responsible for providing childcare, school and education, living and work support and social services for people with deafblindness, CDH and CFD have close cooperation with all the public schools, residential services and organizations that provide high quality service services for disabled individuals.

**For more information, contact the various organizational websites ([www.cdh.rn.dk](http://www.cdh.rn.dk), [www.cfd.dk](http://www.cfd.dk), [www.dovbindfodt.dk](http://www.dovbindfodt.dk)) as well as the DbI Conference [www.dbi2017denmark.com](http://www.dbi2017denmark.com)**

<sup>3</sup> The Nordic Welfare Centre ([www.nordicwelfare.org](http://www.nordicwelfare.org)) is a small corporate member of DbI

<sup>4</sup> The Centre for Deaf ([www.cfd.dk](http://www.cfd.dk)) is a small corporate member of DbI

<sup>5</sup> The National Board on Social Services ([www.dovbindfodt.dk](http://www.dovbindfodt.dk)) is a small corporate member of DbI



**Able Australia has a long association with Deafblind International and cordially invites worldwide colleagues to join us at this prestigious conference.**

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# DbI Network of the Americas Conference

APRIL 15–18, 2018 / Cape Cod, Massachusetts / Resort and Conference Center at Hyannis



**D**eafblind International and Perkins School for the Blind are excited to host the first-ever DbI Network of the Americas Conference. Don't miss this rare chance to network, learn and have fun with leaders in the field of deafblindness from Canada, the United States, Latin America and the Caribbean.

### Partnerships for lifelong learning

We're all stronger when we work together. Our conference theme – Partnerships for lifelong learning – acknowledges the importance of teamwork. By partnering as educators, service providers, consumers, policymakers, advocates and family members, together we can offer a lifelong array of support for the deafblind community – spanning from early intervention and K–12 education to programs, services and products for adults. Be sure to join us!

*“Partnerships for  
lifelong learning”*

### REGISTRATION

**Early Registration:** opens August 1 and closes October 31

**Regular Registration:** opens November 1 and closes February 28

Register at [www.DbiAmericas.com](http://www.DbiAmericas.com)



Hosted by Able Australia, the 17th Deafblind International World Conference will be held on the Gold Coast, Australia on **12-16 August 2019**.

Mark this date in your diary and watch this space for more information.

For information, email us at [dbi2019@ableaustralia.org.au](mailto:dbi2019@ableaustralia.org.au) or visit [www.ableaustralia.org.au/dbi2019](http://www.ableaustralia.org.au/dbi2019)

# 1st International Conference ASSISTIVE TECHNOLOGY and DISABILITIES Rome 4 – 6 October 2017

The Rehabilitation Center of the Lega del Filo d'Oro<sup>1</sup> (Osimo, AN) will celebrate its 50th year of activity in October 2017. Over this long period, the Center has worked to ensure children, young people and adults with deafness and multisensory disabilities receive assistance, education and rehabilitation. To celebrate this important occasion, the Lega del Filo d'Oro is preparing various initiatives, including an International Conference on assistive technology for people with disabilities.

Together with the Taylor and Francis Group<sup>2</sup>, the Lega del Filo d'Oro are organizing the 1st International Conference on **Assistive Technology and Disabilities**, to be held in Rome from October 4th to 6th, 2017 .

The Conference will reflect a growing emphasis on the use of Assistive Technology in the work with persons with developmental disabilities. It will focus on the beneficial impact of such technology on assessment, education, and rehabilitation programs involving these persons.

Among the topics being touched upon during the Conference are:

- the development and assessment of new Speech Generating Devices suitable for persons with blindness and/or dual sensory disabilities
- the development and assessment of technological solutions that may allow self-management of non-verbal instruction cues for activity engagement
- the development and assessment of telemedicine strategies.

This event is open to all professionals working with people with special needs such as psychologists, family doctors, education and rehabilitation professionals, engineers, speech-language pathologists, occupational therapists, and augmentative communication experts. The Conference also welcomes students with special interests in the area, representatives of education and rehabilitation services, family associations, university-associated organizations as well as independent manufactures of assistive technology devices.



The poster for the ATAD 2017 conference features a background image of Rome. It includes the following text: 'ROME OCTOBER 4-6, 2017', 'ATAD ASSISTIVE TECHNOLOGY AND DISABILITIES FIRST INTERNATIONAL CONFERENCE', 'FIRST ANNOUNCEMENT', 'SCIENTIFIC COMMITTEE' (listing Prof. Giulio Lancioni, Dr. Patrizia Ceccarani, Prof. Carlo Ricci, Prof. Grazia Miglino, Prof. Arturo Langa, and Dr. Brian Salmons), 'CONFERENCE VENUE' (Università Pontificia Salesiana, Istituto di Psicologia - Aula Paolo VI, Piazza dell'Aeneo Salesiano, 1, Rome (Italy)), 'LANGUAGE' (The official languages are English and Italian. Translation is available), 'SAVE THE DATE', 'ORGANIZING COMMITTEE' (listing Dr. Rossano Bartoli, Dr. Patrizia Ceccarani, Prof. Arturo Langa, and Dr. Brian Salmons), 'PROGRAMME TOPICS' (Speech generating devices, Video prompting and other visual cues, Computer-aided evaluation, Telemedicine strategies), 'POSTER SUBMISSION' (Deadline: July 20th, 2017), and 'Information and registration: www.atadconference.org atadconference.secretary@bydyesilec.com'. Logos for Lega del Filo d'Oro, Taylor & Francis, and Istituto di Psicologia are also present.



For further request and information please visit the Conference website: [www.atadconference.org](http://www.atadconference.org)

Patrizia Ceccarani (cd@legadelfilodoro.it),  
Scientific Director, Lega del Filo d'Oro Onlus  
– Osimo (AN) Italy

<sup>1</sup> Lega del Filo d'Oro ([www.legadelfilodoro.it](http://www.legadelfilodoro.it)) is a large corporate member of DbI  
<sup>2</sup> [taylorandfrancis.com](http://taylorandfrancis.com)

# International Conference: Communication in the context of congenital deafblindness – ten years of study

## How knowledge and practice develop

Marleen Janssen

On November 15, 16, and 17, 2016, the DbI Communication Network and the Department of Special Needs Education and Youth Care organized an international conference at the University of Groningen<sup>1</sup> to mark the 10th anniversary of the Pedagogical Sciences Master's in Communication and Deafblindness. This event was sponsored by support facilities such as Royal Dutch Kentalis<sup>2</sup>, Bartimeus<sup>3</sup>, Norden (Nordic Centre for Welfare and Social Issues)<sup>4</sup>, Kalorama<sup>5</sup> and SWODB (Foundation for Scientific Research on Deafblindness)<sup>6</sup>

The DbI Communication Network consists of Marlene Daelman (Belgium), Flemming Ask Larsen (Denmark), Paul Hart (Scotland), Marleen Janssen (Netherlands), Anne Nafstad (Norway), Jacques Souriau (France), Inger Rodbroe (Denmark), and Ton Visser (Netherlands). Together they are responsible for the content of the Master's in Communication and Deafblindness at the University of Groningen.

There were 122 participants from 18 different countries from all over the world. The largest delegations came from Norway, Sweden, the Netherlands, Denmark, Belgium, and the United Kingdom. There were also representatives from Brazil, Canada, Croatia, the Czech Republic, Finland, France, Germany, Ghana, Malawi, the Russian Federation, Taiwan,

and the United States of America.

It was an interesting program with plenary presentations, workshops, round table sessions, posters, and films.

Guests were welcomed by the Chair of the University Board, Prof. Sibrand Poppema during a welcoming reception in the beautiful Academy Building on the Broerstraat in Groningen. He told us that this Master's Program in Communication and Deafblindness, and the research related to it, was in his opinion one of the most interesting scientific areas connected to the Faculty of Behavioral and Social Sciences. He especially appreciated the impact it had on and the connection with society. "Complex problems can be solved by this kind of research," according to Poppema.

In addition, the new Dean of the Faculty, Prof. Kees Aarts, was fascinated by the videotapes presented by Anne Nafstad and Marlene Daelman during their keynote speech. Professor Alexander Minnaert welcomed the guests on behalf of the Department of Special Needs Education and Youth Care. He is more familiar with the content of the program, because he has collaborated on several PhD research projects about deafblindness.

The conference was organized to study the theoretical perspectives used in the Master's program and to develop new topics. For an

overview of the program, see the website: [10yearscdbmaster.nl](http://10yearscdbmaster.nl).

The keynote presentation was provided by Anne Nafstad and Marlene Daelman, entitled: "Excursions into the richness of human communication: theory and practice during and before the 10 years of the international program on Communication and Congenital Deafblindness." They provided an overview of developments in the studies of the DbI Communication Network (formerly the Working Group on Communication) over the past 25 years, and where and how the Master's program is related to their work.

During that 25-year period, they worked together with scholars from various scientific disciplines. Marlene and Anne illustrated the different topics in a very interesting way using microanalysis of several sample videos. The topics addressed were well known to people in the deafblind field. The speakers also referred to the scholars who came to international conferences organized during those years.

This initiative all began at the 3rd IAEDB European Conference, Potsdam, Germany (1993) with the theme, "the personal contribution of the person with congenital deafblindness," a theme from developmental psychology and early communication development. In 1996, during the first Paris

<sup>1</sup> [www.rug.nl](http://www.rug.nl)

<sup>2</sup> Royal Dutch Kentalis ([www.kentalis.nl](http://www.kentalis.nl)) is a large corporate member of DbI

<sup>3</sup> Bartimeus ([www.bartimeus.nl](http://www.bartimeus.nl)) is a small corporate member of DbI

<sup>4</sup> The Nordic Centre for Welfare and Social Issues ([ordicwelfare.org](http://ordicwelfare.org)) is a small corporate member of DbI

<sup>5</sup> Kalorama ([www.kalorama.nl](http://www.kalorama.nl)) is a small corporate member of DbI

<sup>6</sup> <https://swodb.nl>

## Conferences

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conference of the Communication Network, the themes 'immediate imitation', 'directedness to the other' and 'emergent self-other awareness' were the key topics. Jacqueline Nadel of the University of Paris brought the 'black book' which addressed the robust discovery of social directedness in humans from infancy. This book served as a great inspiration to the members of the Communication Network. Nadel brought her collaborators along to this Paris conference, including: Luigia Camaioni, Colwyn Trevarthen and Michel Delau. Bertil Bjerkan from Norway also made a point during that conference that there was a difference between social and communicative interaction, and that communicative interaction was always triadic and much more complex than social interaction.

The themes the Communication Network were interested in were focused around 'differentiating forms of social contact and different types of gestural sequences'. The video of 'Thomas and the blue tunnel' was viewed by Luigia Camaioni. She was invited to lecture about the difference between imperative and declarative gestural sequences. Camaioni pointed out an example of declarative referential gesturing and tactile pointing by Thomas, which inspired not only the Communication Network but also many people in the deafblind field.

After that discovery, attention focused on themes such as 'sustained conversation' and 'meaning making'. The scholars Georg Lakoff and Sarah Taub were also invited to speak. The tradition of cognitive linguistics in the US involved theories about embodied meaning in language. When Taub, a sign language linguist from Gallaudet University<sup>7</sup>, applied the work of Scott Lidell to sign language analysis, she could immediately analyze the embodied cognitive

image structures underlying the form of gestures and utterances.

At the same conference, Per Aage Brandt, a cognitive semiotician from Denmark, was invited to speak. He analyzed the possible meaning of utterances and signs using mental space theory. Flemming Ask Larsen, one of our Network members, is one of his students. This explains the place of both 'cognitive linguistics' and 'cognitive semiotics' in the Master's program. They involve tools that enable the analysis of potential meaning in communicative utterances that are difficult to understand.

Another new theme of the Communication Network was 'the discovery of Bodily Emotional Traces or BETs. Working together with colleagues, a Masters Student Gunnar Vege, systematically experimented with transforming embodiment theory into bodily tactile communicative practice with his pupil Ingerid. In the documentary film TRACES, the CRAB-sequence showed that there was a basic potential sign component embodied in this, which can be called a Bodily Emotional Trace or BET. Since then, BETs have been described in several theses by Master's students.

The making of meaning is a very rich topic, and the Communication Network has already used terms such as 'co-creation' and 'negotiation about meaning' in their work.

In creating the Master's program, a proper theoretically grounded foundation or common theme is necessary. This was found in the theory of 'dialogicality', known from the Norwegian professor Ragnar Rommetveit with his orientation towards the Russian philosopher Bakhtin. The Communication Network invited Ivana Markova and Per Linell, two of Rommetveit's collaborators, to speak. While still in the process of exploring the relevance of

concepts, this theory has already appealed to many students.

Through some of the studies, it has been found that people with congenital deafblindness engage in 'linguaging' even though these individuals have very little language in the linguistic sense. They demonstrate a strong communicative agency in spite of very few linguistic skills; they can indicate when they feel that their voice is being heard.

Still, it is a big question how people with deafblindness can have access to culture in a way that is clear and systematic. Eija Lundqvist suggested and evaluated the procedure of tactile overhearing in multi-party interactions, an approach that seems to be very useful and that has been adopted by several Master's students.

But according to Marlene Daelman and Anne Nafstad the journey is not over yet. It is very important to stay focused on communication in terms of finding ways to stay in dialogue, in spite of asymmetry and tension. They believe the Master's program can boost the academic community's interest in studying the interesting theme of human communication further. This would mean studying it from a diversity perspective. People with deafblindness show individual and bodily tactile variations in universal core processes of human communication. Looking at this from a diversity perspective, this Master's program can be very useful for professionals who are interested in analyzing communication not only in persons with deafblindness but also in people with other disabilities and complex communication needs.

A response to the keynote presentation was given by Professor Wied Ruijsenaars of the University of Groningen was entitled: 'Congenital Deafblindness and human communication. Or how much is 6 x 9 again?' Wied Ruijsenaars complimented the

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<sup>7</sup> [www.gallaudet.edu](http://www.gallaudet.edu)

work done in the International Master's in Communication and Deafblindness Program. He stated that in a relatively short period of time a 'knowledge explosion' had occurred thanks to the hard work of not only Master's students but also PhD students at the University of Groningen. Ruijsenaars was very positive about the research on meaning-making, and liked the microanalytical methods of analyzing and evaluating with the new video and computer technologies used in the Master's program. He also liked the explicit connection to the macro-perspective of human communication and education. However, as a professor in the field of learning disabilities (his expertise), he also had some interesting critical points for consideration in the future: a) Examine not only co-constructivism but also direct and systematic instruction for learners with severe learning disabilities; b) consider that learning processes are helped by the analysis of possible intervention steps (Music mixer model, Ruijsenaars, 2005); and c) examine the same video samples from different theoretical viewpoints. Dialogical theory is an important source of inspiration, but do not overlook other theories.

The second plenary presentation was by Professor Ivana Markova, from the University of Stirling, Scotland. We are very familiar with her work from earlier conferences and seminars. Ivana Markova is always very enthusiastic about our Master's program; she even refers to it in her latest book (Markova, 2016)<sup>8</sup>. Markova was invited to talk about the methodological issues involved in transforming the dynamic nature of a dialogue into an empirical project. First, she started by explaining the main presupposition of dialogical perspectives: "the mind of the Self and the minds of Others

are interdependent in understanding and creating meaning of social realities, as well as in interpreting the past, experiencing the present and imagining the future."

Dialogical approaches have their origins in numerous theoretical traditions, starting with Socrates and Plato, up to contemporary approaches inspired by Bahktin, pragmatism by James and Mead, and hermeneutics and sociocultural theories based on Vygotsky.

Markova stated: "The problem of designing dialogical methods goes hand in hand with the theoretical issues of dialogicality. Dialogical approaches are holistic and dynamic, and analytical procedures go against the complexity of interactions in larger contexts and against their multivoicedness".

Markova further worked out several examples of how to generalize from single case studies. Case studies allow for theoretical generalization of research findings as well as for generalization of practices in professional services. One example of the concept 'dialogical learning' was worked out using the analysis of Frank Berteau in his Master's thesis (2010), where he came up with the concepts 'educational learning' and 'dialogical learning', along with the concepts of 'attachment trust' and 'dialogical trust'. According to Markova, these concepts can be applied and investigated using different Self-Other dyads, and applied to different learning situations. These kinds of concepts create additional opportunities for more advanced studies into the additional qualities of dialogical learning and the possibilities of theoretical generalization. She suggests that dialogical communication in congenital deafblindness makes it possible to reflect upon and discuss concepts that remain hidden in non-problematic communication.

The third plenary presentation was given by Professor Stephen von Tetzchner, University of Oslo, entitled 'Language Development: Valuable observations'. Because the full text will be presented later this summer, I will give a short summary here of the most important topics: language development and observations, meaning-making, initiating and replying to joint attention, first and third person perspectives, creating and understanding shared context, communicative affordances, internalizing and externalizing language, how to generalize, and scaffolding. The full text will be available later this year in the *Journal of Deafblind Studies on Communication* (jdbsc.rug.nl).

A response to the plenary presentation of Von Tetzchner was prepared by myself, Marleen Janssen, University of Groningen, and entitled: 'Concepts of Von Tetzchner connected to Master's studies on communication'. First, I explained how the Master's program in Communication and Deafblindness is connected to Special Needs Education, the department where the program is organized. The types of studies done in this Master's program mainly involve case studies on communication and deafblindness. Every study makes a contribution to the evidence base of the deafblind field, where we are trying to establish 'evidence based practice', which means that methods are theoretically underpinned, evaluated in terms of their effects, and followed up by solid implementation. I linked several of Von Tetzchner's concepts to theses by Master's students, such as meaning-making, joint attention, from internalizing to externalizing, languaging, and scaffolding. An overview of Master's theses that cover other concepts such as social interaction, assessment, peer interaction, touch,

<sup>8</sup> The Dialogical Mind: Common Sense and Ethics (Cambridge University Press 2016)

gesturing, exploration, intervener support, dance, challenging behaviors, and identity construction, as well as an overview of the PhD theses on deafblindness from our research group in Groningen, were also provided. The topics covered include affective involvement, intersubjective meaning-making, dynamic assessment of communication, tactile strategies in communication, and motivation to learn. I then asked the audience to actively recruit new Master's students, and to write articles for *Deafblind International Review* and the *Journal of Deafblind Studies on Communication*. We need more PhD and postdoctoral research in our field, and international research collaboration is also necessary.

The fourth plenary presentation was delivered by Professor Shaun Gallagher entitled, 'Embodied intersubjective understanding and communication in congenital deafblindness'. We were not familiar with this scholar from any of the earlier conferences, but we did know him, because one of the Master's students, Kirsten Schou, used his theory on embodied cognition for her Master's project. Gallagher tried to explain three different theories regarding social cognition: Theory Theory, Simulation Theory, and Interaction Theory (Gallagher, 2017). He emphasized Interaction Theory as the most useful one for people who are deafblind. Interaction Theory sees mental states as being embodied and observable in interaction. Gallagher sees social cognition much more dialogically, which is evidenced by studies that distinguish between primary and secondary intersubjectivity. The capacity for direct perception of the intentions of others develops very early in life; with the development of joint attention occurring somewhat later, when the capacity for forming joint intentions for joint actions also occurs. Grounded

in this basic intersubjectivity, a child without disabilities develops competency in communicative and narrative practices, which provide further resources for understanding others, without the necessity of mindreading.

Gallagher prepared for this conference by studying about blindness, deafness, and deafblindness. He found that action perception in blind and deaf individuals was different compared to individuals without disabilities, speculating that for persons who are deafblind, there may be a 'personal model' of social cognition that could be beneficial. He also referenced the work of McInnes and Treffry on 'intensive interaction'. His most concrete recommendation was to incorporate alternative forms of communication into the individual's own form of existence and to look at deafblindness as a complete form of existence.

Jacques Souriau and Kirsten Schou had the difficult task of following up on the Gallagher lecture and connecting it to the Master's program. In his introduction, Jacques Souriau connected the concepts of body-schema and body-image to the concept of Bodily Emotional Traces; the concept of imitation by a child vis-à-vis the concept of immediate imitation by the communication partner, and the role of space in gestures and language. In his response to the lecture, Jacques sparked some interesting discussions that elaborated on, differed with and complemented Gallagher's ideas.

While Gallagher is in favor of the Interaction Theory idea, Souriau stated: "In the Master's program there is a complementary tension between Interaction Theory and Theory Theory. When Interaction Theory fails, it is necessary to rely temporarily on Theory Theory strategies; that is, conscious inferences based on analyses of clues that are available and observable (i.e., actions, gestures, movements,

facial expressions, linguistic utterances)". He referred to analytic tools that are based on the semiotic content of expressions, using the 6-space model, or their bodily construction using the Real Space Blend model, and the emphasis on the dynamics of joint attention.

Souriau concluded that there was consensus on several aspects: The dynamics that transform unconscious bodily processes into conscious cognition are crucial for symbolic developments; inseparability of gestures, space and linguistic forms in symbolic communication and language; the necessity to find strategies to overcome low readability problems, and the need for approaches that prepare for the understanding of narratives.

Kirsten Schou impressively illustrated several theoretical concepts with a video clip of her own student who is congenitally deafblind. She was able to analyze and explain this in a very detailed scientific manner.

The fifth plenary presentation was given by Professor Per Linell. The Communication Network knows Linell from earlier conferences; we use his book: "Rethinking Language, Mind and World Dialogically" as a handbook in the Master's program. In his presentation entitled 'Dialogue and the birth of the individual mind: with an example of deafblindness', he commented on the relationship between general dialogical theory and the analysis of interaction involving persons with congenital deafblindness. He used the video of Gunnar Vege and Ingerid with the CRAB as an example, concluding that, with regard to deafblindness, the following points of 'extended dialogism' are important: Dialogism is not limited to verbal language; it focuses on a broader range of sense-making activities, including the use of signs, gestures, practical actions, and sensory explorations of the outer world within reach;



it accommodates the common feature of asymmetry between participants in communication, and the role of integration of perception and action is even more obvious in the case of touch than in making sense through other communicative resources. Per Linell ended his presentation with these remarks:

“In cases of communication with a person who is congenitally deafblind, it seems obvious that we cannot talk about entirely symmetrical and completely shared understandings.”

During the conference, not only were there plenary presentations but also no fewer than 20 workshops conducted by Master’s graduates and participants from other countries. The alumni covered many topics such as identity construction, affective involvement, creativity in dialogue, agency, the role of intervenors, discovering specific support needs, joint attention, meaning creation, graphic and tactile supports, action research and knowledge transfer, embodied cognition and intersubjectivity. Abstracts from these workshops are being published in the Special Issue on this conference in the *Journal of Deafblind Studies on Communication*<sup>9</sup>.

The other participants were Carolyn Monaco from Canada, who gave a very interesting presentation about the Intervenor program for people with deafblindness at George Brown College<sup>10</sup> in Toronto, and Shirley Maia and Vula Ikonmidis from Brazil, who presented an overview of services at Ahimsa-Grupo Brasil<sup>11</sup> in Sao Paulo. Ingrid Korenstra gave a presentation about outdoor activities at Bartimeus in the Netherlands.

On the Wednesday and Thursday of the conference, round tables discussions were organized, in which alumni led discussions between participants and plenary

speakers aimed at emphasizing the connection between theory and daily practice for people who are deafblind. These sessions were highly appreciated.

In addition to these activities, interesting poster sessions were presented every day, and stimulating films were screened. For an overview of the posters, see the JDBSC website. The films shown were: one film of over 100 years old from the Oberlinhaus in Potsdam<sup>12</sup>, a film of the Rafaël school in Sint-Michiëlsgestel<sup>13</sup> in 1965; a film entitled ‘Touché’ offered by Jacques Souriau from France and two artistic films of André Ahrends from the Netherlands, entitled “First Encounter” and “Touched”.

On Thursday, the last day of the conference, a social gathering was organized by the alumni in the evening. They put on a show in which they satirized all the different kinds of anecdotes about the lecturers in the Master’s program that everyone enjoyed very much.

On a sadder note, the moment came that evening when we had to say goodbye to Inger Rødbroe and Ton Visser. They are stopping their work for the DbI Communication Network after more than 25 years. This conference provided the perfect event to do that with a special Lantern AWARD-ceremony. With a memorable speech by Anne Nafstad and a beautiful musical number by Marlene Daelman on the flute, the retiring members, Inger and Ton, were each presented with a nice lantern, because they shed their light on the content of communication for so many years. Guests went on to enjoy disco music and dancing until late in the evening.

(For more detailed information see website 10yearsdbmaster.nl and the Special Issue of *Journal of Deafblind Studies on Communication* (jdbsc.rug.nl)).



DBI WGC 2016 Lantern Award

For more information, contact **Dr. Marleen Janssen** (h.j.m.janssen@rug.nl), Department of Special Needs Education and Youth Care, Faculty of Social and Behavioral Sciences, University of Groningen, the Netherlands.

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<sup>9</sup> jdbsc.rug.nl

<sup>10</sup> www.georgebrown.ca

<sup>11</sup> www.grupobrasil.org.br

<sup>12</sup> www.oberlinhaus.de

<sup>13</sup> https://www.kentalisonderwijs.nl/Rafael/

# Nordic cooperation in the field of deafblindness

## The Nordic cooperation

**T**he Nordic cooperation is one of the world's most extensive forms of regional collaboration. It comprises Denmark, Finland, Iceland, Norway and Sweden, as well as the Faeroe Islands, Greenland and Åland.

The Nordic cooperation is both politically, economically and culturally rooted. The Nordic community works for a stronger Nordic region in the world.

The Nordic Welfare Centre<sup>1</sup> is an institution under the Nordic Council of Ministers and works in the following areas:

- Public health
- Labour market inclusion
- Disabilities (including deafblind activities)
- Welfare policy
- Welfare technology
- Integration

The Nordic Welfare Centre prepares concrete proposals for politicians, compiles research results and arranges Nordic and international conferences, all with ties to current welfare issues.

Experience from the Nordic countries in the welfare policy field is gathered and compiled. The results are distributed in publications that are available on the Nordic Welfare Centre website.

Experience and good examples are distributed through networks of Nordic experts and at seminars in the Nordic countries.

It is also important for the activities to create meeting places and dialogues between politicians, researchers and practitioners.

## History of the deafblind activities (which are a part of the Disabilities issues)

### A Nordic community among teachers of pupils with deafblindness

The rubella pandemic in the 1950s and 1960s led to many children being born with deafblindness. These children were different from other children with disabilities that were known before, and there was a need for new methods in education. Inspired by the contact with international colleagues, committed teachers developed the 'Deafblindness field' as a shared area of knowledge in the Nordic region in the 1960s. They crossed country borders to find colleagues with whom they could exchange experiences. The collaboration became a network that created a horizon for knowledge development broader than the individual institutions and countries could offer. Strong, bold individuals

supported each other in the development of pedagogical approaches for this new group of pupils. The cooperation was necessary to develop the work and provide each other encouragement and support. Informal visits to each other's operations were later replaced by organised annual Nordic meetings.

### Nordic Staff Training Centre for Deafblind Services (NUD)

At these conferences, the possibility was discussed of establishing a joint Nordic supplementary training programme for teachers of pupils with congenital deafblindness. This was raised to a political level, and in 1981, the Nordic Staff Training Centre for Deafblind Services (NUD) was established by the Nordic Council of Ministers (NMR). NUD quickly became a meeting place for the development of knowledge and expertise, not just for teachers, but also for other professions. The location was "Dronninglunds Slott"<sup>2</sup> in Denmark.

Over the years that followed, course activities at NUD attracted many different categories of staff who worked with people with deafblindness. NUD was a base where colleagues from the Nordic countries

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<sup>1</sup> Nordic Welfare Centre ([www.nordicwelfare.org](http://www.nordicwelfare.org)) is a small corporate member of DbI

<sup>2</sup> [www.dronninglund-slot.dk](http://www.dronninglund-slot.dk)

*“The Nordic cooperation is one of the world’s most extensive forms of regional collaboration.”*

developed an identity as staff members who worked with people with deafblindness, an identity that sometimes eclipsed the professional identity.

NUD filled several functions. Nordic staff members in the deafblindness field were able to exchange experiences there that generated new knowledge as a part of a gradual development from an idealistic attitude to the development of knowledge-based methods. It was also a protection against burnout and isolation, and offered self-confidence and strength in the national work. The special atmosphere at Dronninglund formed the framework of many cooperative projects and NUD developed into a popular meeting place for both Nordic and international professionals from various disciplines.

There was a thirst for more knowledge, better understanding and a shared focus, and many informal working groups arose. A part of them later developed to become formal networks with longer lifetimes, and some of them are still highly current.

#### **Reflection over one’s own work and common Nordic knowledge development**

At conferences and in other meetings with international colleagues, it became clear

that there was a uniform view of knowledge in the work with people with congenital deafblindness. The education and habilitation were interdisciplinary and built on many years’ experience, at the same time that it was influenced and inspired by new impulses from various fields of knowledge.

A success factor for knowledge development in the Nordic cooperation was when NUD held a conference in 1990 on new perspectives in the work with people with congenital deafblindness. It was an attempt to start a process to clarify and specify the theoretical framework that formed the basis of the work with people with congenital deafblindness in the Nordic region. Where do we stand? What can we get from others? What is happening in the deafblind world? Can a Nordic theory be defined?

With a common recognition that “everything is integrated with everything else”, a seed was sown of an even more conscious reflection on the staff’s own work. The Nordic cooperation became even more important, and the possibilities were opened to create a common Nordic strategy in the work with people with congenital deafblindness. The results came two

years later in the form of the book ‘Förutsättningar för kommunikation med personer med medfödd dövblindhet’ [Conditions for communication with people with congenital deafblindness]. It served as a textbook and was also a confirmation of the practical use the individual countries had for the Nordic cooperation.

In the 1990s, national resource centres were built up in several of the countries and the course activities at NUD changed as a result of this. The basic course in congenital deafblindness was defined as a national responsibility. NUD contributed competence development for consultants and counsellors, who guided and taught at the national level. As the courses have become national, a Nordic working group was created that worked out a common framework for the content of the basic training courses. This curriculum was cross-border between the countries and was to be revised at regular intervals. The curriculum is now prepared for both congenital and acquired deafblindness. The one for congenital deafblindness is translated into English.

To strengthen the overall Nordic cooperation, tie countries together and coordinate efforts, the

*“One challenge we are facing is reaching out with the knowledge to the professions that traditionally have not participated in deafblind courses. Or staff who work with people with deafblindness, but not in the areas that have the specific knowledge needed to be able to offer the right efforts.”*

Nordic Leaders' Forum for Deafblind Issues was established in 1994. The forum still exists, and meets once a year (see below).

NUD strived for the same priority between congenital and acquired deafblindness. However, it was not as easy and natural to maintain a similar Nordic cooperation in acquired deafblindness, even if the need existed. It was not the same given staff groups that existed for congenital deafblindness and it was difficult to make a basic course a reality. There were working groups that discussed various forms of cooperation, and a guide was developed with general knowledge about acquired deafblindness and the need for various interventions.

Growing numbers of people with deafblindness have also contributed their experiences and life stories at Nordic and international conferences. This has provided deeper understanding of what life and everyday activities can

look like with deafblindness. A Nordic network gathered this knowledge and experience of living with acquired deafblindness. The collected material forms the basis for the book 'Livsomställning vid kombinerad syn- och hörselnedsättning/ dövblindhet – ett inre arbete över tid' [Life adjustment and combined Vision and Hearing Disability/Deafblindness – an internal process over time], which was translated into English and published in 2011 (Nordic Welfare Centre).

A working group has also prepared a Nordic definition of deafblindness. The first common Nordic definition of deafblindness was formulated in 1980. It has since been revised a number of times and the latest version was adopted at the Nordic Leaders' Forum on Deafblindness in 2016 (see article in 58th edition of DbI Review).

### **Deafblind activities today**

In 2009, the Nordic Council of Ministers decided that

NUD and a number of other institutions that worked in the social field would together form the institution called the Nordic Welfare Centre. The office has now also been moved from “Dronninglunds Slott” to central Stockholm in Sweden, but the activities are conducted throughout the Nordic region.

So as the deafblind activities are structured now, they are included in the disabilities area, and are a part of the whole work on these issues. They form, however, their own operation with their own operational planning. There is a strength in integrating the deafblind issues into general disability work, where work is done, for example, on implementing the UN Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>3</sup>, while still taking advantage of what is specific to the disability of deafblindness.

Every year, the leaders of the various deafblind organisations in the countries meet at the Nordic Leaders' Forum for Deafblind Issues (see above in the article) to discuss common challenges and exchange experiences. There, a need is also addressed as to which issues they want to collaborate on in the upcoming year, and a plan for the year is compiled on this basis.

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<sup>3</sup> <https://www.un.org/.../desa/.../convention-on-the-rights-of-persons-with-disabilities.ht...>

What was previously described as working groups, which among other things developed the Nordic definition of deafblindness and curricula for basic courses in deafblindness for staff, are appointed at these meetings. One challenge we are facing is reaching out with the knowledge to the professions that traditionally have not participated in deafblind courses. Or staff who work with people with deafblindness, but not in the areas that have the specific knowledge needed to be able to offer the right efforts.

The other events that are held are courses for staff, conferences and meetings in knowledge-developing networks. The work of the networks is under way over a longer period of time, and they have the task of preparing and developing knowledge, as well as passing that knowledge on. This largely concerns communication development among people with congenital deafblindness and cognition in relation to congenital deafblindness. In connection with the networks meeting, staff and relatives are also invited to a one-day course or information sessions about the knowledge being developed, and the work being done in a specific area. Today, there are the following

four active networks: The Cognition Network, Tactile linguistics, Communicative relationships and CHARGE. Several of the networks have distributed publications and work on providing an evidence basis to the methods and approaches used. Some of these publications have been translated into English, and you can find them on the website.

The deafblind activities at the Nordic Welfare Centre also collaborate with the Deafblind Nordic Cooperation Committee (DBNSK). The Nordic cooperation is a prerequisite to be able to develop the knowledge in the deafblind field as each individual country has too small a population of people with deafblindness to pursue it nationally. The Nordic cooperation also contributes to opportunities for a stronger international cooperation. As a part of this, the Nordic Welfare Centre's deafblind operation is a member of the Dbl Board.

**Maria Creutz, Project Manager Deafblind Issues, Nordic Welfare Centre (maria.creutz@nordicwelfare.org)**

**Knut Johansen, Senior advisor in Deafblindness, Signo Vivo (knut.johansen@signo.no)**

**WEBSITE:**

[www.nordicwelfare.org/sv/Ovrigt/About-us](http://www.nordicwelfare.org/sv/Ovrigt/About-us)

[www.nordicwelfare.org/sv/Om-oss/Funktionshinder/Dovblinda](http://www.nordicwelfare.org/sv/Om-oss/Funktionshinder/Dovblinda)

**FACEBOOK:**

Nordens välfärdscenter – dövblindområdet

***“The Nordic cooperation also contributes to opportunities for a stronger international cooperation. As a part of this, the Nordic Welfare Centre’s deafblind operation is a member of the Dbl Board.”***

Argentina

## Educational Practices in formal and informal settings in Latin America: Educational Pathways for children 6 to 12 years old

By Graciela Ferioli and María Antonieta Vázquez

### MANUEL'S STORY

**M**anuel leaves with his family every morning with the aim of learning and understanding the simple things of life. He lives his routines close to home in his neighborhood in Latin America. He and his intervenor routinely walk down the road from his home to a nearby bakery where they take a snack.

This experience is usually a simple everyday activity for most children, but in this story this task becomes an educational experience that has a direct impact on Manuel's quality of life.

Every interaction has been well prepared in advance by the intervenor and the child. This has been thoroughly planned in regard to time and routines to ensure that

there will be a successful interaction between the two partners. The child participates by making his own choices which is a source of high motivation for him.

Each one of the elements that weaves through this experience reflects in one hand on the characteristics of formal education and on the other the opportunity to experience real life situations.



Left: In this picture the intervenor suggests the activity to Manuel  
Middle and right: Manuel practices his right to choose.



Left: cues using a real object  
Middle: cues using a pictogram: "We are going to eat what we bought"  
Right: Taste described with sign language

*“Each one of the elements that weaves through this experience reflects in one hand on the characteristics of formal education and on the other the opportunity to experience real life situations.”*



### From action to research

This article has been developed within the framework of the research project **Educational Practices Facilitating Learning for Children with Multiple Disabilities** at the Universidad Católica de Córdoba, Argentina<sup>1</sup> that explores practices that: a) facilitates learning in children (ages 6 to 12) with multiple disabilities, and b) promotes social inclusion in different settings in Latin America and Spanish speaking Caribbean.

Last year's educational practices have been the subject of several research studies. Because of the different cultural settings where these have been developed, a number of educational policies have been developed from the various conclusions of the studies.

The educational practices that this research observed and analyzed become accepted opportunities to increase social inclusion (Escudero Muñoz, 2009<sup>2</sup>). A good educational practice will be one that avoids the risk of social exclusion. Knowing the risks will also allow researchers to better describe aspects of the educational process required in specific contexts, including various policies, strategies

and curriculum development.

The objective of this particular research was to identify the various formal and informal educational practices necessary to facilitate learning acquisition and social inclusion. This will be done through a thorough identification and description of the practices, analysis of the various educational environments, and other aspects that encourages social inclusion.

To undertake this initiative, a qualitative and quantitative work proposal was designed to understand the different circumstances of Latin America and Caribbean area. From a quantitative point of view, the methodology for collecting and analyzing information will be to implement a protocol of observation using video observations. For the qualitative perspective, the intention will be to describe and interpret educational practices, while taking into account the range of cultural diversity.

### Learning from others

Education in Latin American and the Caribbean area has developed a broad range of scenarios. Many factors have been identified as obstacles to inclusive education, including poverty, crisis in governing, lack of education quality and lack of inclusion. On the positive side, research is showing that a new culture of acceptance is developing and along with the growth in networking and teamwork, there are

indications of positive changes towards developing inclusive education policies.

The research team is currently receiving videos demonstrating good practices of inclusive education from such countries as Panama, Mexico, Argentina, Dominican Republic, Brazil, Ecuador and Chile. These videos also demonstrate good inclusive practices in hospitals, Non-Governmental Organizations, community service settings and within families.

This research is intended to identify and describe successful educational scenarios –even beyond the school sphere – that are proven to increase children's education and development opportunities in diverse settings amid vastly different educational challenges.

**For further information contact: Graciela Ferioli (g\_ferioli2000@yahoo.com.ar) or María Antonieta Vázquez (Maryyvazquez70@gmail.com)**



Graciela Ferioli



Maria Antonia Vazquez

### Argentina continued

<sup>1</sup> www.uccor.edu.ar

<sup>2</sup> ESCUDERO MUÑOZ, Juan Manuel (2009) Profesorado Revista del currículum y formación del profesorado BUENAS PRÁCTICAS Y PROGRAMAS EXTRAORDINARIOS DE ATENCIÓN AL ALUMNADO EN RIESGO DE EXCLUSIÓN EDUCATIVA – VOL. 13, N° 3 – Universidad de Murcia

Australia



## Western Australian ‘Heroes’ Deafblind Camp, 2016

Senses Australia<sup>1</sup> was very proud to host the ‘Heroes’ Deafblind Camp, November 18–20th, 2016, at the Woodman Point Recreation Camp<sup>2</sup>, Coogee Western Australia. The WA Deafblind Camp provided an opportunity for people who are deafblind to come together, to catch up with friends old and new, to share lived experiences and engage in recreational activities and outings in an environment that was safe, accessible and supportive. Fifty seven Deafblind people from all over Australia and two people from Scotland and the UK attended the camp this year. To ensure campers had the best experience, volunteers who numbered over one hundred were there to provide 1 to 1 communication and sighted guide support. Volunteers were trained in the areas of: What is Deafblindness, causes, impact, communication, Do’s and Don’ts and Sighted Guide training, along with tactile and hand over hand training. Many of the volunteers put in fifteen hours days and were tireless in their commitment and support of our campers. A huge thankyou to all the

dedicated volunteers new and old who embraced our deafblind community; we couldn’t have done it without you. Feedback from deafblind campers on the volunteers included:

“All those new volunteers learn from me with Hand over Hand communication, I teach them not problem, very good and most learn how to guide with me, no problem wonderful so amazing :-)”

“I enjoyed this camp and leaned much from others; all the volunteers were fantastic”

“Very relaxed and the volunteers worked hard to ensure everyone could participate”

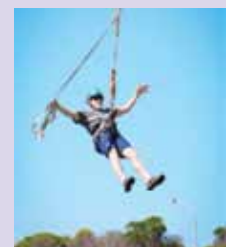
“Well organised, the communication support and volunteers enabled me to communicate with others, meet new friends and new challenges”

On arrival on Friday afternoon campers were given a little time to settle in and orient themselves to the campsite. A meet and greet was held on the beach with

a Tug of Wars competition – with lots of muscles, bluff and buster and a few good laughs along the way. This was followed by the evening meal and catching up with friends old and new.

On Saturday campers participated in a variety of recreational activities, including: early morning boot camp and beach walks, flying fox, archery, tandem bike riding, stand up paddle boards, indoor roping challenges in the Cube, massages, coffee at the beautiful Coogee Marina and a great variety of craft activities, including a group totem pole project. Saturday afternoon the activities continued and a historical tour was provided detailing the interesting history of this heritage site.

Saturday evening campers and volunteers alike were entertained with a round of Bingo, followed by comedy with Rob Roy and Rae Gibson. Campers and volunteers were full of enthusiasm and partied well into the night. Everyone embraced the ‘Heroes’ theme with some fantastic costumes and lots of happy snaps were taken in the photo booth to remember the night.



<sup>1</sup> Senses Australia ([www.senses.org.au](http://www.senses.org.au)) is a large corporate member of DbI

<sup>2</sup> [www.dsr.wa.gov.au/camps/locations/woodman-point](http://www.dsr.wa.gov.au/camps/locations/woodman-point)



Awards were delivered for Best Costumes and Best Volunteers. Many thanks to our stoic judges: Debbie Karasinski, CEO Senses Australia and Matthew Wittorff, Manager, Deafblind Services.

Campers were asked to feedback on what they liked the most about camp, comments included:

“Socialising and meeting new people and old friends”

“The opportunity provided for campers to meet and get to know other campers”

“The paddle boarding, tandem riding and The Cube were excellent activities for active participants. These activities were very well run with “experts” giving good guidance”

“Activities were the best – paddle boards, tandem bikes and bush walks”

“Amazing friendship. I thought it was great having a clown entertaining the DeafBlind Campers on Friday night and letting them touch her. Loved everything even climbing the ladder of the bunk beds was exercising! Photo Booth photos are worth having. Suffering Camp withdrawals!!!!!!”

On Sunday morning campers were on the move early again and given a variety of activities to choose from. Many went to explore the Coogee Marina while others enjoyed hula hooping, yoga, craft; stand up paddle boards and massages.

The West Coast Street Rod Club generously donated their time and provided joy rides to campers in their amazing vehicles throughout the morning.

All too soon it was time to leave the camp for this year. We all enjoyed a goodbye lunch and the speeches began. Many campers got up and expressed their happiness at having been able to participate in this fantastic experience. A few comments from volunteers and campers are listed below:

“I enjoy spending time with everyone and seeing deafblind participants mixing socially with each other. I observed there was a lot of mixing, even between people with different communication modes. This was excellent”

“The best camp I’ve ever attended, I LOVED EVERY MINUTE OF IT”

“Experienced lots of new things and was smiles all weekend”

“Senses did a fantastic job”

“Loved socialising and meeting new people and old friends”

“My first time. Want to go again”

“I just want to say as a carer how important camps such as this one are to me – my brother is not the only one who appreciates your efforts – A big thankyou to all involved from me!!”

“Thoroughly enjoyed myself as a volunteer. Hope to be back in 2018!”

“Very huge THANK YOU for very wonderful camp weekend; DB people had very great time”

This camp was generously supported by Lotterywest<sup>3</sup>, WA Charity Direct<sup>4</sup>, Able Australia<sup>5</sup> and Senses Australia. If you would like to see more of the photographs and comments from camp please visit us at the Deafblind West Australians website <http://www.dbwa.org.au/> and on Facebook <https://www.facebook.com/search/top/?q=wa%20deafblind%20camp%202016%20photos>

**Karen Wickham**  
Camp Coordinator /  
Senses Australia  
Email: [karen.wickham@senses.org.au](mailto:karen.wickham@senses.org.au)

**Australia continued**



<sup>3</sup> [www.lotterywest.wa.gov.au](http://www.lotterywest.wa.gov.au)

<sup>4</sup> [wacharitydirect.com.au](http://wacharitydirect.com.au)

<sup>5</sup> Able Australia ([www.ableaustralia.org.au](http://www.ableaustralia.org.au)) is a large corporate member of DbI

Australia  
continued

## The Ironman journey, Busselton WA Dec 4th 2016

This is the story of Darren Stevens's journey to complete a full Ironman Triathlon. Darren has Usher's Syndrome

### The preparation:

**M**y journey to complete a full Ironman (IM) started in August 2015. As a starting point, I decided to first complete a half IM as a prerequisite. I managed to get some support with my training preparation through a local cycle & tri club. Finding likeminded people to support long distance triathlon can be quite difficult, so I took advantage of any offers made available. The half IM went really well; I was allowed under race rules to have 3 guides for each leg. I completed the half IM in a respectable time and felt confident (maybe a little overconfident) in my goal to achieve the full distance. I also completed the HBF Run for a Reason<sup>1</sup> & the Perth Half Marathon<sup>2</sup>. It was in the Perth Half Marathon that I picked up an injury which was to haunt me in the coming months. The Iliotibial Band Syndrome (ITB)<sup>3</sup> is a common running injury which can linger. I pressed on with as much training as possible along with intense sessions in Physiotherapy, massage and acupuncture. By now I was only four months out from the full IM. Not only was this injury causing me frustration, I also received a telephone call from the IM race director

advising me I could only have one guide for the full event. At this stage I thought my race was already over; being injured and trying to find one person prepared to complete this distance seemed an impossible task. I phoned around and approached my local Triathlon Club but with the time available and the event approaching fast all leads came to a dead end. Enter Paul Garwood, Orientation & Mobility Specialist from Senses Australia<sup>4</sup>; I had run with Paul in the HBF half marathon and found we worked well together as a team. I discussed my predicament with Paul; he advised me not to cancel and had a plan. Having survived our first & only bike session before the IM I felt my goal might just be achievable, however, we had yet to swim together!! Guide swimming relies on a reasonably similar stroke rate and lots of confidence. Being tethered to the guide via a leg rope attached to my waist along to his ankle can have its difficulties. Fortunately, we had the opportunity to practice our swim on two successful occasions indicating I was now beginning to believe we might actually make the start line.

### Race weekend.

The amount of logistics needed even getting to the start line is immense. First of all we arrived at the wrong address for our weekend accommodation. Once we found the correct address we then had to attend registration in Busselton, a separate race briefing, a tour of transition, hanging our race kit, and finally racking the bike. I was exhausted on the night before, without having even started the race. As soon as I closed my eyes the alarm sounded, it was 4:30AM.

Wetsuits, goggles, Tri suit, swim cap, and timing chip needed to be organized. Before I could even realize that this was the day, I was putting on my wetsuit. The race director advised us we would be starting at 6:50AM. The hooter sounded and off we went. I was thinking that the plan was to stop at the 2k or halfway point for a motivational breather. This was not to happen as 1500 swimmers caught up to us near the half way point and Paul decided to stop for fear of being trounced. When we finally hit shore, I was relieved, despite only swimming 1 hour 15 minutes. The swim had built my confidence before going into the bike leg.

<sup>1</sup> <https://www.hbfrun.com.au>

<sup>2</sup> <https://www.wamc.org.au/major-events/perth-half-marathon>

<sup>3</sup> [www.runnersworld.com/tag/it-band-syndrome](http://www.runnersworld.com/tag/it-band-syndrome)

<sup>4</sup> Senses Australia ([www.senses.org.au](http://www.senses.org.au)) is a large corporate member of DbI

As we left on the bikes with a 180k ride in front of us, my adrenaline was pumping. Our plan was to split the bike leg into 2 parts and not to think about the whole distance. We soon settled into a comfortable cadence and started passing a few competitors. The ride consisting of two laps was mentally challenging to complete. When we started our second lap I was doubting my ability to continue turning the cranks for another three hours, often into a strong headwind.

No matter how comfortable your cycling shorts are nothing can prepare your bottom for 6 hours and 20 minutes in the saddle. The cheer we received both on route and when we completed the bike ride was simply amazing. I could not believe we had completed two legs in just under 8 hours. I felt amazing but glad to get off the bike.

I then started the third event, running with flying confidence; but to my horror I had left my orthotics in my other shoes which were back at our accommodation. This affectively meant I was about to run 42K in running shoes without in soles. However, we started well and I felt my pace would not be affected by my shoe issues. Unfortunately, this was to last for the first 10k!! The dreaded ITB and a growing pain in my right knee became more and more concerning.

Words can't describe the agony of the next 32K. Fading light took my remaining vision; I was simply running empty and blind. The course had distance markers. At one stage Paul thought we were on our last lap, which lifted my spirits

until we worked it out we had in fact two laps to go. By now I was hitting the wall more than I have ever experienced. I needed a breather and was strongly considering pulling out. The crowds cheered me on; they were getting to know me and could see my pain and suffering. This kept me going. I set small achievable goals by moving from point to point rather than laps. I was already in a world of pain; not having any soles in my shoes were causing even more pain. Not hearing or seeing and in great pain I struggled on. I befriended an 'ambo' who strongly encouraged me to finish.

Eventually we hit the final lap and I was told the finish shoot was in sight. The combined roar of the crowd and my immense pain caused a certain amount of delusion; suddenly I had crossed the finish line and became an Ironman. The rest is a bit of a blur. I became overwhelmed with emotion and cried, I felt absolutely beaten but the IM medal around my neck said I had won the battle.



### The recovery:

Sun burnt, barely able to walk, stiffer than a door post, I awoke realising it had not sunk in yet. We left Busselton like wounded warriors. Paul and I had been stuck together for 14 hours 42 minutes through hell & high water. It took three days for me to walk properly by myself; my skin peeled for weeks, and since I haven't even thought about Triathlon!! This was by far the hardest and most challenging experience I have ever done in my life. I did IM the hard way but learned the impossible is not a fact, it's an opinion.

**Darren Stevens**  
(djs.1991@yahoo.com)



**Australia  
continued**

## Anne Sullivan Centre reports



Augmentative and alternative communication

**3**rd March 2017 was International World Hearing Day. The Anne Sullivan Centre celebrated World Hearing Day through promoting the use of augmentative and alternative communication methods. In doing so, we visited two well-known local businesses to facilitate what we called “The Augmentative Communication Challenge”. Employees of the companies were taught how to sign the ISL alphabet in 10 minutes and were then given 30 seconds to sign a word into their partner’s hand which they felt described them best. The challenge was that their partner was blindfolded and wore earplugs while they signed to them. It was fantastic to see how quickly the participants were able to recognise the letters that were being spelled into their hands and we felt it really demonstrated that there is no such thing as “disability”. Our aim was for participants in the challenge to recognise the ability in others and understand that when efforts are made to understand and remove the barriers to social inclusion, everybody benefits.

For more information about the AnneSullivan Centre see their website: [www.annesullivan.ie](http://www.annesullivan.ie)

### Jordan

## Modalities of Communication with Deafblind persons in the Arab world

**M**s Asma Masa’adeh is Deaf. She finished a 2-year Diploma course as a Teacher of Children with Special Needs and achieved a B+ marks for her BA degree.

In 2013 she was invited to do a course on Deafblind education at Perkins School for the Blind in Boston, USA, under the Hilton scholarship programme. She spent one year there, together with one of the Institute’s interpreters for Arabic Sign language. Perkins also provided an ASL interpreter. This was the first time Perkins had a Deaf trainee from abroad and it turned out to be a very positive experience for all around.

Asma has worked with deafblind children since 2012. She is head of teacher training at the Institute and is now the deputy head of the Deafblind unit. Recently she created a flyer (opposite page) that shows the various methods of communications used by deafblind persons which the Institute has published for public use.

For more information contact  
Asma Masa’adeh at [hlid@gmail.com](mailto:hlid@gmail.com)



*Quote from Asma: “Deafblind children are neglected everywhere. My heart’s desire is to visit schools and centres in Jordan and go to other Arab countries to train people in the care and education of deafblind children.”*

The Holy Land Institute for Deaf and Deafblind Children (HLID)

P.O. Box 15, Salt 19110, Jordan, tel: +962(0) 5 3554953  
 fax: +962(0) 5 3554951, e-mail: HLID@go.com.jo



"The Holy Land Institute for the Deaf" (HLID) seeks to enable and prepare Deaf, hard-of-hearing and deafblind children, as well as people with other sensory and physical disabilities, for inclusion and participation in their families and communities in a meaningful way, and to make their valuable contribution to an inclusive civic society (in the Middle East).

English Manual Alphabet

Aa	Bb	Cc	Dd	Ee	Ff	Gg	Hh	Ii
Jj	Kk	Ll	Mm	Nn	Oo	Pp	Qq	Rr
Ss	Tt	Uu	Vv	Ww	Xx	Yy	Zz	1
2	3	4	5	6	7	8	9	10

Touch Alphabet (Braille)

a	b	c	d	e	f	g	h	i
j	k	l	m	n	o	p	q	r
s	t	u	v	w	x	y	z	0
1	2	3	4	5	6	7	8	9

TACTILE SIGN LANGUAGE

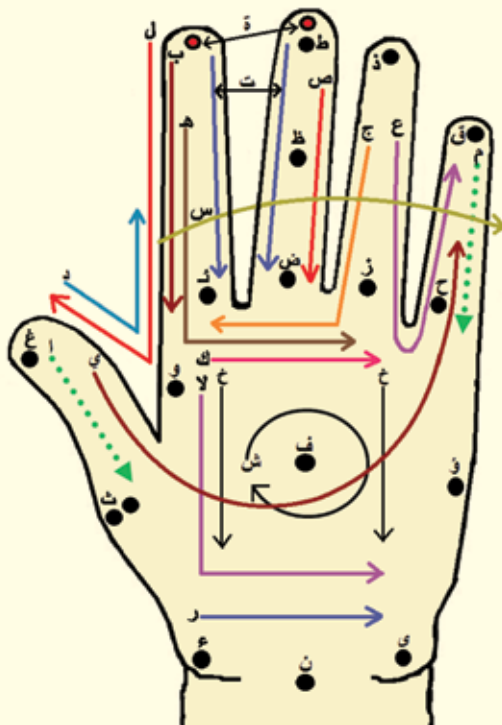
DEAFBLIND ALPHABET

The right, active, hand of the sender forms the letters onto the left, passive, hand of the Deafblind recipient and vice versa.

A	B
C	D
E	F
G	H
I	J
K	L
M	N
O	P
Q	R
S	T
U	V
W	X
Y	Z

LORM ALPHABET

لغة الإشارة الأبجدية اللصية "لورم"



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مؤسسة الأراضي المقدسة للصم والعم المكفوفين

ص.ب: 15 السلت 19110 الأردن  
 هاتف: 532 4521 (0) 5 355 4953 - الفاكس: 532 4521 (0) 5 355 4951  
 البريد الإلكتروني: hlid@go.com.jo

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الأبجدية الإشارةية العربية الأردنية

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ر	ز	س	ش	ص	ض	ط	ظ	ع
ف	ق	ك	ل	م	ن	هـ	و	ح
ي	أ	ب	ت	ث	ج	د	ذ	ر
ز	س	ش	ص	ض	ط	ظ	ع	ف
ق	ك	ل	م	ن	هـ	و	ح	ي
١	٢	٣	٤	٥	٦	٧	٨	٩

الأبجدية اللصية (براييل)

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Jordan  
continued

## The Deafblind Unit at the Holy Land Institute for Deaf and Deafblind Children, in Salt, JORDAN

### Intelligible Language

**W**hen I see a new child, I observe what s/he does, to try and find out what she wants. As teachers, we translate the body language of the child to signs and hands-on sign language so that their communication becomes accessible and intelligible for people around the child. The goal is for their little hands to begin to speak.

### Expectations

Some of the children have additional disabilities. To serve and educate them we have to be observant and creative, and our expectations should ALWAYS remain high, even if the achievements take forever and are perhaps not what we hoped for. Meanwhile the child may have developed other abilities.

### Patience and Control

Working with Deafblind children and young people

takes enormous patience and compassion. Perhaps the most difficult lesson for our new staff to learn is not to dictate to the children what to do, but to try and encourage them to express themselves and their wishes, for us to support and guide them.

### Individual Educational Plans

For all children in the unit, whatever the level of their capacities and capabilities, we make individual plans, which are followed by teachers, volunteers as well as – most importantly – the parents and families in the child's environment.

However, the IEP is not a recipe, but it is a guide to keep individual programmes on track and to record what the child has achieved. Most of the time the child indicates where she wants to go, what she wants to do, where are the gaps in behaviour and knowledge, etc., and then it is up to the teacher or the responsible person to adjust the IEP according to the child's progress and desires, and not to adjust the child to the programme.

### Deafblind Children Prefer Deaf Environments!

It has been our experience that Deafblind children thrive in a Deaf environment. Lots of Deaf children and young people as well as staff who are Deaf provide more and better communication using

hands-on Sign language. In fact we continually see how much Deafblind children learn from their Deaf friends and peers, and how they develop more quickly and easily under Deaf teachers.

Ms Khadijeh has a BA degree in Social Work. While studying for her degree she joined the Holy Land Institute's Deafblind Unit as a teacher in 2007. Soon her great interest and exceptional aptitude as well as compassion for the job became evident and she became the head of the unit in 2010. She has remarkable rapport with the deafblind children and young people in her unit, which meanwhile has grown from 2 children in 2001 to 2 adults and 11 children (aged 3 – 16) today. The teaching staff number 5 deaf and 8 hearing personnel and the resident staff number 4. There are an additional 2 volunteers and approximately 10 +13 deaf students for duties during meal times and for after-school hours.

**For more information about the Deafblind Program at the Holy Land Institute for Deaf and Deafblind Children, contact [Khadijeh@gmail.com](mailto:Khadijeh@gmail.com)**



Two Deaf teachers with deafblind student Mohammed, studying a caterpillar

**Quote from Khadijeh:**  
*"We have to share the lives of the deafblind on their terms, to be able to understand them and to share with them our wonderful world".*



Deafblind Miriam playing with 3 Deaf students



Kawthar, a deafblind – multiple disabled pupil, with her Deaf teacher



Deafblind Mohammed with his teacher and a hearing child

## The perception and awareness of ‘things spiritual’ in Deafblind Children

Jordan continued

Brother Andrew A.L. de Carpentier

One of the most challenging, but also perhaps the most interesting aspects of working with deafblind children and young people, is to try and “read” them. Especially with children who are still in the pre-language stage, or who might never develop intelligible signed, written or spoken language, learning to read them is absolutely essential.

We try to enter their world of communication and read their body language, their reactions to outside events and to things that impact their lives. We learn to interpret the sounds and the typical movements they make to express their emotions. Indeed, once we begin to understand we are astounded by the level of communication that is going on.

But what about abstract thought? Is there thought for tomorrow, or for the day after? How can we know when

we don’t know how to ask? When they don’t have the language to answer? What about spiritual things? Is there a possibility that they may experience and interact with something / someone beyond ‘our senses’? Are their inner eye, their inner ear, so finely attuned and responsive that they are able to perceive ‘that other world’? Do they perhaps sense the presence of spirit-beings, of angels?

### This leads to the ultimate question:

People like me, with normally functioning senses, are dulled by the constant bombardment of visual and aural signals that clutter our brains, causing us to become ‘deaf’ and ‘blind’ to the gentle signals from within.

Are our “poor” deafblind children perhaps meant to be kind reminders for those of us who have become ‘blind’ and ‘deaf’

ourselves, who have lost the ability to communicate with the worlds beyond..., the world of the Creator!?

For more information about Holy Land Institute for Deaf and Deafblind Children, contact Brother Andrew at [hliid@go.com.jo](mailto:hliid@go.com.jo)



Kawthar



Murhaf



Mohammed

Malawi

## Deafblindness in Malawi and Zambia: the Signo program



Sr Emma Kulombe



Sr Emma Kulombe, Eril Mbeki and Jaques Souriau

If you go to Chisombezi, near Blantyre, the second biggest city of Malawi, you may have the chance to visit one of the treasures of this little country of 17 million people: the Chisombezi Deafblind Centre<sup>1</sup>. The 'African Queen' of this little Kingdom is Sr Emma Kulombe whose energy and incurable optimism gathered enough support and engagement to create the first school for Deafblind children in Malawi. Do you know where Malawi is? This 840 km long, 160 km wide country is squeezed between the countries of Tanzania, Mozambique, Zimbabwe and Zambia in East Africa. In this region where many countries have been plagued by political conflicts and violent competitions for access to mineral resources, Malawi stands out as a peaceful country, perhaps because it does not benefit from such rich and strategic resources as oil or gold.

The Chisombezi Deafblind Centre project started in 2004. It took some time to build, one piece at a time, the dormitories, the class rooms, the kitchen, the facilities for the staff, the power generator and the water supply. Sr Emma knocked at many doors to find money and political support. She never gave up!

On Sunday, the 23rd of October 2016, I had the privilege, on her invitation, to spend several hours on this tiny little spot on the planet where 20 deafblind children live together close to each other, in a warm (sometimes very hot, I must say), secure and sensitive human environment. The teachers were kind enough to allow me to meet and make the acquaintance with each of the children who were present. They have different styles, due to the variety of their etiologies, sensory impairments and developmental profiles. Some

of the children fall somewhere in between being strictly defined as having congenital or acquired deafblindness. However, with each of them it was possible to establish a sustained and joyful contact without breaking, intrusively, their relationship with their teachers. With these encounters, I got the practical knowledge I needed to get on board with a big project that I will describe in detail as follows.

In 2003, the General Secretary of the Norwegian NGO, the Signo Foundation<sup>2</sup> (a 120 year-old Church-based organization which deals with 700 Deaf people with additional disabilities and deafblind people), visited Malawi on invitation from the Norwegian Church Aid<sup>3</sup>. During that time, he met Sr Emma and visited the Maryview School for Deaf Children<sup>4</sup> (near Blantyre) and (in the same area) the Montfort Special Needs

<sup>1</sup> [chisombezideafblindcentre.weebly.com](http://chisombezideafblindcentre.weebly.com)

<sup>2</sup> [www.signo.no](http://www.signo.no)

<sup>3</sup> <https://www.kirkensnodhjelp.no>

<sup>4</sup> <https://www.facebook.com/pages/Maryview-School...Deaf-Children/745270135517260>



Education College<sup>5</sup> where teachers for children with disabilities receive their training. He noticed that services for Deafblind children did not exist yet in Malawi and decided to use his professional relations to help start a project for these children. Sr Emma was invited to Norway in 2004, and until 2007, this new Chisombezi Deafblind Center had received financial support from the Norwegian Church Aid with technical advice from the Signo Foundation. In 2007, the Norwegian Church Aid felt they had not enough technical competencies to continue its support for such a project and handed it over to the International Department of the Signo Foundation. Signo receives financial support from the Norwegian government for these type of activities.

Since 2008, the project is in the capable hands of Kenneth Verngård, a senior professional with the Signo Foundation, who started his work in 1995 as a social care assistant while studying to become a teacher. After some years working within the Signo Foundation, and



Kenneth Verngård

with international studies replacing his teacher studies, he joined the international department as an adviser for international projects. The ongoing collaboration between the Chisombezi Deafblind Center and Signo has been carried out through three successive periods (2007–2009, 2010–2015 and now, 2016 to 2019), with the possibility of extension for eight more years after that.. To make the project holistic and coherent, three main priorities were proposed: establish a solid infrastructure program (buildings, energy supply, staffing), develop an effective information program including support for the families and provide training for the professionals.

Much has been already been done with regards to the infrastructure: the school has buildings, with a suitable energy supply and a strong team of teachers. An important next project will be to secure an Internet access with WIFI to facilitate international collaboration and sustained access to information.

In addition to the school facilities, the Chisombezi Deafblind Center has developed a decentralized program of support for 65 Deafblind people and their families through a home-based education and rehabilitation services program. Teachers and other social workers identified people who were Deafblind and provided advice to their families about how to improve the quality of life

for their children at home. One of the challenges in this context was to make the information accessible to all kinds of families and communities, including those who are illiterate.

Something helped Kenneth to tackle this problem. In 2010, he met a Zimbabwean colleague who had designed a booklet for professionals working with children with disabilities. He decided to do the same thing for Deafblind children. While the Zimbabwean booklet was text based, Kenneth wanted a booklet based on illustrations to make the information accessible for illiterate parents. He submitted this project to his Norwegian colleagues. Initially they were not enthusiastic, arguing that Deafblind children are so diverse that it was neither relevant nor possible to write and draw simple pieces of advice that would be suitable for all of them. However, Kenneth was stubborn enough to get a few colleagues on board to work on this booklet. And it worked! They managed to prepare essential guidelines about how to live and communicate with Deafblind people. They hired Sølvi Aspen Solvang, a Norwegian ceramist and painter to develop the drawings illustrating the necessary information. The first version was completed in 2015 and made available to users to try out its relevance and readability.

This leads to another important character of this story: Haakon Lie. Haakon

**Malawi**  
continued

<sup>5</sup> <https://www.facebook.com/.../Montfort-special-needs-education-college.../257433240...>



Sr Emma with trainee

is a colleague of Kenneth's in the Signo Foundation, responsible for the housing unit for persons with deafblindness. He took an active role designing the booklet and collaborated with Kenneth to develop awareness and knowledge about deafblindness among professionals and organizations in other African partner countries. His first trip to Malawi was in 2013 which involved facilitating a 3-day conference on deafblindness for 20 people from Malawi and Zambia, which included teachers, community based rehabilitation workers, representatives from the government of both countries, and more. In 2015, Haakon and Kenneth returned to Malawi to try out the booklet during a workshop for teachers and community based rehabilitation workers and during meetings with some families in their homes. Everyone wanted to learn if the booklet was suitable to convey information about deafblindness, that the illustrations

were understandable, and could they fit in with the local culture.

In this context, Kenneth, Haakon and I (as a lecturer of the University of Groningen<sup>6</sup>) went to Malawi in October 2016 to meet Sr Emma for a 2-week intensive program that included several activities: a follow up of the booklet project; a workshop at the Montfort Special Needs Education College to improve the Deafblindness awareness part of their curriculum (in collaboration with the University of Groningen), and an awareness workshop in Zambia for the lecturers of the Zambian Institute of Special Education (ZAMISE)<sup>7</sup>.

Why Zambia? In 2010, Kenneth met Simate Simate, the General Secretary of the Deafblind Association of Zambia<sup>8</sup>, at a conference in Blantyre, Malawi. Simate indicated that services for deafblind people were not yet available in Zambia at that time. Kenneth decided to investigate the possibility to support the development of services in Zambia through a global plan of collaboration between Zambia, Malawi and the Signo Foundation. Through various contacts with the Zambian administration, two main institutions were identified as suitable for this project: the Bauleni Special Needs Project (BSNP)<sup>9</sup> (where a first program for deafblind children would be organized), and the Zambian Institute of Special Education where training the teachers could occur possibly through collaborating with Montfort

in Malawi. Zambia (752 000 km<sup>2</sup>, twice the size of Germany) is a much bigger country than Malawi with a lower density of population (16 million people). Malawi and Zambia are close to each other and share a lot of cultural characteristics. Therefore, it seemed a good strategy to join forces between the two countries with regards to deafblindness.

Håkon and Kenneth came this time with a new booklet that included texts and pictures suitable for the families, as well as guidelines for the professionals to use the original parent's booklets in their consultancy work. This proved to be a success during a workshop in Malawi. The ideas and illustrations developed between Chisombezi and Signo worked quite well in Malawi, with the workshops triggering a lot of relevant questions. Sr Emma and I also facilitated another workshop for the lecturers of the Montfort Institute attempting to create more awareness about deafblindness and preparing a collaborative work aimed at improving the Montfort curriculum on deafblindness. The general knowledge on deafblindness was supported by video analysis sessions, a method that most of the participants had never used.

The following week, the four of us flew to Lusaka, Zambia, for the same activities as in Malawi, but this time facing an audience that had no experience with deafblindness. Håkon and Kenneth facilitated a

<sup>6</sup> [www.rug.nl](http://www.rug.nl)

<sup>7</sup> <https://www.facebook.com/.../Zambia-Institute-Of-Special-Education-ZAMISE/2518165...>

<sup>8</sup> <https://www.facebook.com/.../DEAFBLIND-ASSOCIATION-OF-Z...>

workshop on deafblindness for teachers at the Bauleni Special Needs Project while Sr Emma and I worked with the lecturers of the Zambian Institute of Special Education (ZAMISE).

Along with all these staff development and awareness activities, Kenneth arranged several contacts with administrative authorities of the two countries to organize a future program. For each country, a Memorandum of Understanding was prepared for the purpose of organizing future collaboration between the national administrations, the Signo Foundation and the University of Groningen. For the period March 2017 to February 2018, lecturers from Montfort, ZAMISE, Chisombezi Deafblind Center and Bauleni Special Needs Project will have the possibility to participate in a training program on deafblindness, partly in Malawi and partly

in Zambia. This program will include: a general knowledge of Deafblindness, mobility training, an introduction to the conceptual framework of the booklets on Congenital Deafblindness and Communication<sup>10</sup> (social interaction, gestures, meaning making, language development) and the practice of video-analysis (technical aspects and conceptual framework). Participants will be given a variety of tasks: hands on activities with congenital deafblind children, preparatory literature study before the beginning of the course, supervised literature studies with presentations to the other students, exercises in mobility, guidance and communication adapted to Deafblindness, video analysis and production of a Case Study report. On the basis of this training, the curriculum for the diploma course on

deafblindness for teachers offered at Montfort will be amended and ZAMISE will write up its own for a planned diploma course. Besides, the participants who are interested will have the possibility to join the Master on Communication and Congenital Deafblindness in Groningen if they apply and are accepted by their own administration, the Signo Foundation and the University of Groningen.

Much has been done, and there is still much to do. Something positive is happening for Deafblind people in Malawi and Zambia through this ongoing International collaboration where all partners learn and develop. There are enough people interested and dedicated to this program to anticipate that the whole project will be a success.

Jacques Souriau

**Malawi continued**



Workshop Planning session



Workshop participants at the Montfort Special Needs Education College

<sup>9</sup> [www.allianceforum.org](http://www.allianceforum.org)

<sup>10</sup> Published in 2006 by VCDBF/Viataal, St. Michielsgestel, The Netherlands. Work undertaken by the DbI Communication Working Committee.

## From Exclusion to Inclusion: A Success Story about a Deafblind Entrepreneur Living in a remote area

**V**IHEMA Deafblind Malawi<sup>1</sup> has for the past seven past years been involved in empowering its members through promoting various approaches to overcome the prejudice about Deafblindness in the country. We wanted to present an appealing success story to demonstrate the capabilities of individuals within the Malawi Deafblind community to improve their personal welfare. Our story is about Geoffrey Mghima, a 43 year Deafblind man who lives in Mzimba District, located about 200 km north of Lilongwe, the capital of Malawi.

When VIHEMA Deafblind Malawi, embarked on an identification and assessment program of individuals with deafblindness some years ago, we located Geoffrey who was at the time working in his small tobacco garden. Geoffrey, just like any other man in his neighborhood, also wanted to improve his lot and improve his family's economic situation. The project staff were surprised when they asked Geoffrey if there was any other business he would like to venture into. He was quick to ask the staff what was the possibility of obtaining livestock to further develop his economic situation. Geoffrey Mghima consequently became among the first 30 Deafblind individuals to benefit from an initiative supported by the Finnish Foundation, ABILIS<sup>2</sup>.

From the beginning of the program, beneficiaries like Geoffrey, were provided with two goats (1 male and 1 female). The deal was that once this first pair of goats bred to produce a pair of offspring, they would keep the offspring and pass the original pair to another beneficiary in the program. The



Geoffrey

conditions of this initiative, compelled each beneficiary to safeguard the life span of their individual project; otherwise they would be required to return their contributions. These conditions encouraged Geoffrey to work very hard; as such he became the best of all 30 beneficiaries of the program. His deafblindness definitely did not discourage him from working hard to improve his economic situation.

From his humble beginnings a few years ago starting with two goats, he now has a stock of more than fourteen goats. After giving away his starter pair as required, he is now able to call himself a successful entrepreneur. As well as his healthy livestock business, he also maintains a healthy tobacco garden, which together allow him to earn enough to purchase adequate food and clothing for his family as well as supporting his siblings' education; a situation that was not possible before.

This successful story strongly demonstrates that Deafblindness as a disability can be overcome with practical individually based support programs.

**For more information,  
contact VIHEMA at: vihema.  
deafblindmalawi@gmail.com**

### Nicaragua

## International Partnership Aids Deafblind in Nicaragua

Tracey Veldhuis and  
Mélanie Gauthier

**I**n 2015, DeafBlind Ontario Services<sup>1</sup> (Canada) and Mo Gård<sup>2</sup> (Sweden) partnered to offer expertise through training and mentoring to Asociación de Sordociegos de Nicaragua<sup>3</sup> (ASCN) or Deafblind Association of Nicaragua, for individuals who are living with deafblindness in Nicaragua. The partnership identified a need for training around daily living skills in this country. The Canadian Helen Keller Centre<sup>4</sup> (CHKC) also offered their support for this collaboration.

Tracey Veldhuis (DeafBlind Ontario Services) and Mélanie Gauthier (CHKC) spent 10 days in Masaya, Nicaragua in February 2017. The aim was to help teachers and individuals who are deafblind become more independent and able to participate more fully in their communities using low-tech devices and resources that are available locally. This collaboration was made possible by a grant from the Luke Four Foundation in Peterborough, Ontario<sup>5</sup>.

Before entering the classroom, Veldhuis and Gauthier spent some time immersing themselves in the reality of life for adults who are deafblind in Nicaragua. They visited four different family homes to see how they live, and learn about their challenges and how they support themselves.

Toolkits from Canada were handed out to help students implement the newly learned strategies. The toolkits included supplies like elastics, clips, puff

<sup>1</sup> VIHEMA Deafblind Malawi is a mini corporate member of DbI

<sup>2</sup> www.abilis.fi/en

**Veldhuis tells the story:**

“Many of the challenges that individuals who are deafblind in Nicaragua face are similar to those in Canada... but there are other challenges that were new to us.

Individuals who are deafblind in Nicaragua do not receive any support or financial assistance from the government. They must be resilient in supporting themselves.

Several of the individuals asked for support in cooking, as they prepare meals over an open fire. The ability to cook directly impacts their independence.

With cooking over an open flame comes concerns about safety and reducing risk of injury. We hope to address safe cooking training on a future visit to Nicaragua, as this was something the individuals identified as being important to learn.

We shared techniques including marking and identifying food containers in their homes with elastics, identifying ways to mark their clothes with dots of puff paint, and more, so they can make their own choices and live more independently.

We also provided training in a classroom setting to members of the organization, as well as teachers working with children who are deafblind. The training we provided was in the format of “train the trainer”, to ensure that they will be better equipped to support the people they work with, and share the information with others. The teachers plan to apply these learnings in future lessons.”

paint and small magnifying sheets. For some students, receiving resources that are basic and inexpensive in Canada went beyond their wildest dreams.

“One woman commented that she never thought she would ever own a magnifier”, commented Gauthier, “These magnifiers were only 33 cents in Canada. She was over the moon.”

The partnering organizations acknowledge much more needs to be done. They are hoping to continue this partnership with the Nicaraguans in the future with resources, support and training.

In the meantime, the partnering organizations are supporting ASCN to attend the upcoming DbI conference in Denmark, something they have never had the opportunity to do in the past. DeafBlind Ontario Services will be presenting at this conference on our experience in Nicaragua.



Participants practising sighted guide



Some participants who attended training



Playing BINGO with adapted cards

**For more information, contact Tracey Veldhuis (t.veldhuis@deafblindontario.com), Deafblind Ontario Services or Mélanie Gauthier (mgautier@chkc.com), Provincial Programs Manager, Canadian Helen Keller Centre**

<sup>1</sup> Deafblind Ontario Services () is a large corporate member of DbI

<sup>2</sup> Mo Gärd is a foundation-owned non-profit business that offers services in support and service, treatment, education and knowledge support. Our focus areas are communication and disability (<http://www.mogard.se/om-mo-gard>)

<sup>3</sup> ASCN is a small corporate member of DbI

<sup>4</sup> chkc.org

<sup>5</sup> <https://www.canadahelps.org/en/charities/luke-four-foundation>

Russia

## Usher syndrome research in Russia

According to unofficial data, the prevalence of Usher syndrome in Russia is estimated at about 15,000 cases per 150,000,000 people. While at first glance this low incidence might seem insignificant, it under rates the significance of dual hearing and vision loss to wards depriving these individuals from key aspects of human communication. This sensory deprivation leads to severe social isolation and associated psychological vulnerabilities, which are issues of significant importance, despite the low incidence of its occurrence.

As far as vision loss is concerned, even 20 years ago few could imagine that scientists would be capable of developing methods to restore vision or at least preventing symptoms of retinitis pigmentosa<sup>1</sup> from progressing. Nowadays we are witnessing scientists from all over the world working miracles and undertaking successful attempts in this direction. Gene therapy, which has now reached a high level of understanding, is one innovative method being used to treat retinitis pigmentosa. This treatment focusses at the very nature of

the disease, radically changing its progression.

Gene therapy which leads to restoring vision and hearing functions in adult humans seemed impossible several years ago. Scientists thought that these genetic disorders could only be treated before birth during embryogenesis. They also assumed that the disease could only be avoided through in vitro fertilisation. Now as multiple techniques and approaches have been tested, we see from experiments that DNA can repair itself in adult human cells if a healthy segment of DNA (gene) is inserted at the appropriate location.

This year (2017) has been marked with several breakthroughs using of gene therapy to reverse deafness and blindness in humans, Specifically, we can say that the gene therapy techniques that are closest to becoming broad clinical application are the use of the RPE65 gene therapy for blindness caused by Leber congenital amaurosis<sup>2</sup> and retinitis pigmentosa, and using CGF166 adenovirus vector to overcome deafness caused by Atonal transcription factor gene mutations<sup>3</sup>.

Since 2016 the Deaf-blind Support Fund So-edinenie (Connection)<sup>4</sup>, in cooperation with the Laboratory Sensor-Tech<sup>5</sup>, CRO Oftalmic<sup>6</sup> and major Russian scientific institutions and clinics have been actively addressing the issue of putting gene methods into Russian practice

for treating blindness and deafblindness.

With a view of undertaking a project to realize the benefits of gene therapy to treat Usher syndrome, we invited 24 deaf-blind people demonstrating typical clinical signs of this condition for further comprehensive medical examinations. In the first phase which was completed in the IV quarter of 2016, the patients' biomaterial underwent bio-informational genetic analysis, for the purpose to detect the 'defects' in their DNA material. In the II quarter of 2017, all patients will undergo high-level ophthalmologic and audiologic examinations together with their genetic analyses data to obtain a complete picture of their condition and register the project at the international resource ClinicalTrials.gov<sup>1</sup> with an opportunity to take part in clinical trial of perspective gene therapy methods.

One of the key goals of this project is to give hope and provide an opportunity for people with retinitis pigmentosa, currently destined to blindness, to get an effective treatment. Moreover, a widespread gene technology implementation in Russia and production of drug-genes on the basis of domestic pharmacological enterprises are planned in the future.

**Andrey Demchinskiy, Laboratory "Sensor-Tech" and Deaf-blind Support Fund So-edinenie (Connection) (email: demchinsky@sensor-tech.ru)**



<sup>1</sup> [www.aao.org/eye-health/diseases/what-is-retinitis-pigmentosa](http://www.aao.org/eye-health/diseases/what-is-retinitis-pigmentosa)

<sup>2</sup> [www.ghr.nlm.nih.gov/condition/leber-congenital-amaurosis](http://www.ghr.nlm.nih.gov/condition/leber-congenital-amaurosis)

<sup>3</sup> [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)

<sup>4</sup> [www.so-edinenie.org](http://www.so-edinenie.org)

<sup>5</sup> [www.sensor-tech.ru](http://www.sensor-tech.ru)

<sup>6</sup> [www.oftalmic.ru](http://www.oftalmic.ru)

<sup>7</sup> [www.ncbi.nlm.nih.gov/pmc/articles/PMC4076126](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4076126)

## The Home Where You Feel Warm

Russia  
continued

For many years, we've dreamt of having our own house for deafblind people, where they'd be living peacefully, interact with each other, and would be safe from the storms of life, although likely feeling lonely. At last our dream has come true! In the autumn of 2016, the So-edinenie Foundation<sup>1</sup> opened its first full-time residence for people with combined vision and hearing disorders in Russia. The project was referred to as 'The Quiet Home'. This beautiful, modern three-storied mansion is situated near Troitsk, in the New Moscow area. Currently there are eight people living in the home – four men and four women. We're old friends with many of them, so, of course, I was eager to talk to them to find out how their life was going there, whether they liked it or not and what they were doing there.

And here I am at the Quiet Home. I'm walking up the wooden stairs to the second floor. I step inside a big room. It's the living room, also serving as the kitchen and the dining room. I can immediately feel the atmosphere of the Home, not like that of a state owned institution, but that of a home where a big family lives. There's a carpet on the floor. There's a cozy sofa equipped with small embroidered cushions. Sitting and talking in this corner is so comfortable! There are two people sitting there right now – two men

named Alexey, my old friends. They are fingerspelling to each other – hand in hand. I greet them; identify myself to them – speaking with both hands simultaneously. The boys understand me, we're happy to see each other! They immediately take me on a tour of the house.

Apart from the living room on this floor, there is a large bathroom with a bathtub. There's also a washing machine. The kitchen has all the necessary things: easily accessible cabinets, a giant fridge, a microwave, and a gas stove. There's also a computer in the living room, as well as shelves full with books.

The third floor of the house has the same layout. There's a bathroom and another washing machine there as well.

Alexey Piseev is a completely deafblind person. He was blind from birth. At ten, he started experiencing hearing loss. Now, even hearing aids are of no help. He communicates by fingerspelling. He grew up in a foster home for the deafblind in Zagorsk (now Sergiev-Posad). Then he ended up in the Klinov foster home for the elderly and the disabled. He lived there for many years. From there he was brought to the Quiet Home. Alexey takes me to his room. He shares it with Mikhail Nikolayev – another former student at a foster home and an inhabitant of the same foster home for the elderly. There are two comfortable beds in the room and a big bedside

chest in-between them. There are two wardrobes as well. Each has his own wardrobe for the first time in their lives.

I ask Alexey: "How do you like it here?"

Alexey Piseev says: "To say I like it here is to put it mildly. I'm truly happy living here, in this house. My soul is now warm after the formal coldness of the foster home. There

*"To say I like it here is to put it mildly. I'm truly happy living here, in this house. My soul is now warm after the formal coldness of the foster home."*



<sup>1</sup> So-edinenie Foundation ([so-edinenie.org/en](http://so-edinenie.org/en)) is a small corporate member of DbI

### Russia continued

are kind and compassionate people around us. But the most important thing is that they teach us to live independently, to do many useful things. I've learned how to iron bed sheets, make candles, and slice apples to make chips. I also love the classes at the carpenter's workshop at the Resource Center in Yasenevo. It's not far from here, they take us to different workshops."

Aleksey also told me that he reads Braille a lot. Books and magazines are regularly brought to the Quiet Home from the library for the blind. Everyone here also loves to read the 'Vash Sobesednik'<sup>2</sup> magazine and they always eagerly await new issues...

Next door there's a women's dormitory. The furnishing is similar. Tatiana Alifertseva lives here. She was alone when I visited – her roommate had gone to her relatives for a little while. The people living here still have their homes, and they can always go there – for a short time, or permanently.

Tatiana is completely deafblind, and has Usher syndrome. Her story is tragic. She was losing her hearing and sight gradually. When she went blind, her husband left her. Her daughter abandoned her deaf and blind mother as well. The Quiet Home ended up being her salvation from severe depression, from which she had been suffering from for a number of years.

Tatiana Alifertseva: "I feel so good here – so calm! I like to make molds at the pottery workshop in Yasenevo. I love cooking, I can make pies. I enjoy knitting, so the Foundation bought me stitching threads and I make various house shoes."

Tatiana showed me the whole bundle of socks and slippers that she made. Needlework is her main hobby that helps her calm down, forget her past.

Aleksey Zhivagin is a handyman, who can truly do wonders with his hands! Aleksey has been blind since childhood, but has partial hearing thanks to a hearing aid. He attended the foster home in Zagorsk, and later lived with his sister's large family in Kuban. Life was boring there – he had no one to talk to and not much to do. Now, at the foster home Aleksey has learned a lot. His crowning achievements, children's toys, were exhibited at various international art shows and some of them are even exhibited at the Sergiev Posad's Toy Museum.

On the third floor of the Quiet Home, in the living room, is the weaving workshop. This is Aleksey's 'workplace'. He learned how to weave while living at the foster home. He likes it immensely. Upon learning about his hobby, the "So-edinenie" Foundation bought a weaving machine and all the necessary materials for him. Now Aleksey weaves various beautiful napkins, coverlets, chair wraps, with great delight.

Aleksey Zhivagin: "I love being at the Quiet Home; there's not a single dull



<sup>2</sup> Vash Sobesednik' (Your Companion) is a magazine for people who are deafblind in Russia.



moment here! I always have something interesting to do. Apart from weaving, I like making molds. I make dishware. I also read a lot. I was attending computer classes at the Puchkovo home for the deafblind and after completing them the Foundation “So-edinenie” gave me a Braille display. I can read books on the internet now. And of course, now there are plenty of opportunities to communicate with others. We’re also often attending different events.”

Indeed, the inhabitants of the Quiet Home go on trips and participate in holidays and festive events. They participated in the Christmas concert in Puchkovo. And quite recently they took part in the festive evening concert during the closing ceremony of the international conference on the issues of the deafblind.

The Foundation is doing everything in its power to make the inhabitants feel wanted, desirable and capable of realizing their creative potentials to fullest extent. It organizes exhibits of their works.

Natalia Shmaeva spent many years at one of the psychiatric and neurological care homes in Moscow. She was the only deafblind person there; she had no one to interact with. Now, living at the Quiet Home, Natalia does not only interact with her fellows in distress, but also with the staff members and guests who often visit the Quiet Home. She eagerly visits the pottery workshop in Yasenevo and she takes great pleasure in participating in various concerts. Natalia’s life has changed for the better; it has become more

interesting, more diverse, and filled with meaning.

And how are the domestic issues being dealt with, who helps the deafblind?

It is no coincidence that ‘The Quiet Home’ project is referred to as ‘the assisted living home’.

There are seven staff members working at the Quiet Home, including a sign language interpreter. They shop for groceries, cook food, help the deafblind with their domestic issues if they arise such as doing the laundry, etc. There’s always a hearing and sighted person working at night. To ensure their safety, the deafblind people are never left on their own.

But the inhabitants also help the staff as much as possible. There are daily shifts. Attendants peel and cut vegetables for dinner, do dishes, and clean the rooms. The most active and skilled of them is Sergei Utkin, who came to the Quiet Home from a foster home. He eagerly mops the floor in every room and does the laundry.

I asked them about what they dream about. It turns out that many deafblind people want to work and earn money. The Foundation has been trying to solve the problem of their employment from the very beginning.

The garage on the first floor has been turned into a workshop. Here they make candles and apple chips. These were handed out to the Foundation’s trustees as Christmas gifts. Now they’re looking for new and accessible types of work.

Indeed, the lives of those who ended up in the worst situations by the decrees of fate did become better



*“People feel that they’re no longer alone in this world.”*

thanks to the Foundation’s care. People feel that they’re no longer alone in this world. They have their own home; warm and cozy where kind and caring people work.

It is imperative that more warm homes like this one be created; one in every region of Russia. For there are many disabled people with combined vision and hearing disorders in the country who are left alone and receive no care from their relatives! Even if someone does not require such an ‘assisted living’ home right now, it may be necessary tomorrow! The deafblind people should not be left to deal with their misfortune alone.

**Natalia Kremneva**  
([gkremnev@gmail.com](mailto:gkremnev@gmail.com)).  
Natalia is editor in chief of Vash Sobesednik. She is also a woman with deafblindness.

Switzerland

## Adapting subtitles for people with hearing and visual impairments

### A new and promising technology

By Nicolas Baertschi

How can you watch television if you have a visual and hearing impairment? This is the question that 200,000 older people in Switzerland with poor sight and hearing will be asking themselves (Spring, 2011). One of the most familiar solutions for deaf and hearing impaired people is the use of subtitles. It is possible, of course, to make subtitles easier to read by moving closer to the television, adjusting the image on the screen

(brightness etc.), improving the ambient lighting and using the remote control. However, this is often not enough to meet the needs of people with a dual disability.

A survey carried out among 10 clients of the Swiss National Association of and for the Blind (SNAB)<sup>1</sup> (Baertschi, 2016) showed that it is difficult for hearing and visually impaired people to follow a programme by reading the subtitles. The main reason for this is that the subtitles appear and

disappear too quickly. Almost half of the people surveyed found that the subtitles are too small. On the majority of current televisions, the subtitles are between 10 and 12.5 times larger than the text in a newspaper. At a distance of 50 cm from the screen, anyone who needs text enlarged more than 5 to 6.3 times will not be able to read the subtitles. As a result, larger subtitles would allow people who can only read text enlarged 6.3 times or more to benefit from subtitles.

### Subtitling technologies

Three subtitling technologies are in use in Switzerland, each of which have a different appearance. The first is teletext subtitling and this is used by Radio Télévision Suisse (RTS)<sup>2</sup>. These subtitles have a good contrast and are generally well received by people with visual impairments.

The second technology is digital subtitling. This currently has poorer contrast than teletext subtitling and is generally more difficult for people with sight problems to read.

The third technology is relatively new and is known as HbbTV<sup>3</sup>.



Figure 1: Teletext subtitles



Figure 2: Digital subtitles



Figure 3: Digital subtitles

<sup>1</sup> snab.ch

<sup>2</sup> <https://www.rts.ch>

<sup>3</sup> <https://www.hbbtv.org>

## “How can you watch television if you have a visual and hearing impairment?”

### HbbTV: a new technology

HbbTV stands for hybrid broadcast broadband TV. In the near future, it should allow the appearance of subtitles on Swiss television channels to be modified. In principle, the features of HbbTV subtitles that can be changed include the size, location, colour (text and background), font, spacing and positioning of the subtitles and the size of the image. The changes could be made in a menu system using the remote control.



Figure 4: Reduced image and normal-sized subtitles



Figure 5: Reduced image and enlarged subtitles.

### Short-term expectations

It is not currently possible to reduce the speed at which subtitles appear and disappear. However, there are technical options for doing so (Linder, 2016). Although HbbTV is available in Switzerland, at the moment the appearance of the subtitles cannot be modified by individual viewers. Negotiations are underway between the associations that represent people with sensory disabilities, RTS and SwissTXT. We can only hope that the results of these discussions will allow people with hearing and visual impairments to adapt subtitles so that they are accessible for everyone.

**“We can only hope that the results of these discussions will allow people with hearing and visual impairments to adapt subtitles so that they are accessible for everyone.”**

The document based on the degree dissertation by Nicolas Baertschi entitled “La lecture des sous-titres à la télévision en Suisse pour les personnes malvoyantes et malentendantes” (Reading television subtitles in Switzerland for hearing and visually impaired people) is available from the SNAB specialist library and in electronic format. An electronic copy can be requested by sending an e-mail to [mueller@szb.ch](mailto:mueller@szb.ch). (Also questions in French or Spanish are possible and will be forwarded to the author of this text and dissertation.)

# Stimulating communication in individuals with deafblindness using an intersubjective developmental perspective<sup>1</sup>

Saskia Damen

**I**n literature, the communication of individuals with congenital deafblindness is often described as delayed or limited. To explain this as a natural consequence of their dual sensory loss may be only part of the story. In the following I will explain how problems in the interpersonal communication between individuals with congenital deafblindness (CDB) and their communication partners can be understood from a socio-cognitive perspective, using Trevarthen's theory of intersubjectivity (Braten & Trevarthen). Furthermore, I will describe how I used this theory for the analysis and support of the interpersonal communication between individuals with CDB and their communication partners.

## Intersubjectivity

My PhD study was the first in which Trevarthen's three developmental layers of intersubjectivity were examined in children and adults with congenital deafblindness (Damen, 2015). Intersubjectivity is, according to Trevarthen, "the ability to share subjective states". In my dissertation I also used "the ability to share meanings" and "self – and other awareness" as alternative definitions.

According to Trevarthen, the ability to share subjective states is an innate ability that can be observed already after birth during social interactions. This ability becomes more complex as children grow older. Intersubjective development is a consequence



of the child's experiences in interpersonal communication, and communication partners play an important role in stimulating these experiences. On the basis of video-observations of interactions between typical children and their mothers when the child was a few weeks old until the child was six, Trevarthen distinguished three layers of intersubjective development: 1) primary intersubjectivity, 2) secondary intersubjectivity and 3) tertiary intersubjectivity. I will describe these layers hereafter.

Sighted and hearing Infants of a few weeks old already show primary intersubjectivity, which is characterized by awareness of the other. This is seen in their active and responsive attitude towards their communication partners and engagement in turn-taking activities. It is not until the infant is about 9 months old however, that he or she starts to show mutual awareness, the characteristic feature of secondary intersubjectivity. At this layer of

intersubjective development, the child is able to share attention with his social partner for objects and to negotiate and share communicative intentions. The main purpose for the communication at this layer is to get something or someone and the communication is therefore called "imperative". Between ages 2 and 6 typical children start to communicate more and more for the purpose of sharing thoughts, which is referred to as "declarative communication". The child now mainly uses symbolic forms of communication. These more complex communication behaviors reflect "a narrative and verbal self and other awareness", which characterizes tertiary intersubjectivity, the third and highest layer of intersubjective development.

## Individuals with Congenital Deafblindness (CDB)

My PhD study was based on the hypothesis that people with CDB are also born with the same innate ability to share meaning as people with normal sight and hearing. However the development of the more complex forms of negotiating and sharing meanings may be delayed or impeded as a result of an interplay between characteristics of individuals with CDB as well as difficulties for the social partners to adapt their interaction strategies to these characteristics. Problems that are often described in the interpersonal

<sup>1</sup> This paper was presented at the conference "communication and deafblindness, 10 years of studies" at the University of Groningen, November 15–17, 2016

communication of individuals with CDB (including misunderstandings, communication breakdowns, and limited symbolic and declarative communication) may be better understood by considering what type of interaction experiences are generally needed to develop and show communication at the three layers of intersubjectivity and how dual sensory loss effects these experiences.

For individuals with CDB and their communication partner it is difficult to experience awareness of the other, since the child is not able to have (sufficient) visual or auditory attention to the other person, preventing their noticing visual and auditory attention by the communication partner and engaging in visual and auditory turn-taking. Mutual awareness is difficult to develop because of the lack of possibilities to share eye gazes or direct the other's attention to something else in a visual or auditory way. Furthermore, the individual and his communication partners may miss each other's communicative attempts and communication partners often do not have the skills to negotiate about the meaning of utterances of the individual in a bodily-tactile way. Without sufficient exposure to coherent and meaningful (bodily-tactile) experiences with symbolic forms of communication or with communication for the purpose of sharing thoughts, these aspects of communication will not be able to develop at all.

### Partner strategies

In my study I found that Trevarthen's theory of intersubjective development was a useful framework to get insight into the interplay between participants with CDB and their communication partners. With the help of independent coders, I was able to reliably measure aspects of communication in

videotaped conversations at the three layers of intersubjective development. This analysis enabled the comparison of individuals with each other and the same individual with different communication partners or the same partner at different moments in time. Such comparisons in my study revealed: differences among the eleven participants with CDB and their 36 communication partners; differences before and after the intervention and differences for the same individual with CDB with different communication partners.

Trevarthen's theory appeared also useful as a guide for supporting interpersonal communication between individuals with CDB and their communication partners. Based on this theory and on the Contact program (Janssen et al., 2003) we developed the High Quality Communication Intervention. This intervention is set up as a training for parents, caregivers and teachers using a coach. The coach supports the individuals by evaluating their interactions using knowledge of intersubjective development and stimulates intersubjectivity in a way that is adjusted to the needs of the individual with CDB.

The coach provides support to the communication partners during two education sessions, five individual and three group video-feedback sessions. In the first 5 weeks of the intervention, the communication partners learn how to attune their behaviors and emotions to those of the individual with CDB, by offering for example tactile initiatives and responses, providing sufficient time for the individual to respond. In the second 15 weeks of the intervention, communication partners are supported in meaning making. For example they learn how to encourage the individual with CDB to indicate if he or she feels understood, by giving more information about the meaning of his or her utterances and creating a narrative of a past experience.

### Case Study – John

The eldest participant in my study was John, aged 49 with profound hearing loss and blindness due to prematurity. John lived in a group home for adults with congenital deafblindness. Before starting the intervention, his caregivers described several difficulties in the interpersonal communication with him. John often showed signs of tension in interaction and would squeeze their hands if his tension became too high. Furthermore, there were a limited amount of topics that he brought to the conversation; for example he mainly used sign language to ask for a snack. Therefore, the caregivers experienced their interactions with John as rather functional than personal. After having received knowledge on the importance and characteristics of communication at the first layer of intersubjective development, John's caregivers evaluated their video-taped interactions with help of the coach, formulating goals to work on. They noticed on the video that John was often searching for contact by reaching beside him, where the caregiver would usually be seated during interactions with him. They were not aware of this before and did not respond to these contact initiatives. They also saw that his tension was rising while repeatedly searching for contact. This tension was noticed, but resulted in avoidance rather than contacting him. During the first phase of the intervention, caregivers started to pay attention to his initiatives, to respond to them in a tactile way and to initiate physical contact with him more often by themselves. This resulted in more dyadic interactions. During the meaning making phase, caregivers evaluated their communication using knowledge of aspects of second and third layer intersubjective development. They noticed that they did not really support conversations with him.

## Stimulating Communication



They did initiate conversations by signing “what do you want?” but when John responded signing “a cookie”, they usually responded by saying “no, finished” and broke off the conversation. During the meaning making part of the intervention, caregivers started to elaborate more on the snack-topic by talking about the things he liked to eat or had eaten that day. They also started to bring in new topics

and experienced that John was able to elaborate on these topics himself or to give more information about what he wanted to share when they encouraged him to do so.

### General results

Comparison of conversations before, during and after the intervention showed significant improvement in communication for John but also for the other ten participants with CDB in the first two layers of intersubjective development. For 7 out of 11 participants, significant improvements were also seen in communication for the purpose of sharing thoughts, which is at the third layer of intersubjective development.

Most effects and the most complex communication was seen when communication partners used meaning making strategies in addition to attunement strategies. Furthermore, we found that communication partners

were able to elicit more complex forms of communication in individuals with CDB by using these forms of communication themselves. Individuals with CDB who only used a limited amount of communication to refer to objects, people or events used this type of communication, relatively more often, after the communication partner displayed this type of communication in the conversation.

**For more information, contact Dr. Saskia Damen (s.damen@rug.nl) Assistant Professor, Special Needs Education/ Deafblindness University of Groningen; Kentalis Deafblindness Center of Excellence**

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# Positioning Interventions to Facilitate Fine Motor Skills in Children with CHARGE Syndrome and/or Deafblindness

Samantha Kublin, Sarah Bis, Diane Smith, and Sarah Maust



Samantha Kublin



Sarah Bis



Diane Smith



Sarah Maust

In the school setting, most activities are presented to children while seated at a desk or at tabletop (Aminian, Hinckson, & Stewart, 2015). Of the numerous professionals and related service providers on a child's educational team, an occupational therapist is uniquely qualified to assess the sensory and motor demands of a given task and/or the environment in which the task is presented (American Occupational Therapy Association [AOTA], 2014). David Brown (2006; 2007), deafblindness educational specialist, explains that challenges in tactile, vestibular, and proprioceptive senses are common for children with deafblindness and/or CHARGE syndrome. Proprioception is defined as the way we can feel where our body parts are in relation to each other without having to touch or look at them (Brown, 2006). The vestibular sense informs us of the position of our head in relation to gravity, enabling us to feel oriented in space (Brown, 2007). Deficits in these sensory systems impact

a child's abilities to participate in school tasks. Individuals with CHARGE syndrome have an impaired vestibular system due to the absence or malfunction of the semicircular canals in the inner ear as well as an impaired proprioceptive system as evidenced by low muscle tone. Both contribute to impaired balance and postural insecurity for people with CHARGE syndrome (Brown, 2003). Due to these sensory deficits and low muscle tone, David Brown (2003) suggests that there is a marked preference for children with CHARGE syndrome to assume a supine or a side-lying position. This is in line with an occupational therapist's understanding of the child's need for a stable base of support and postural control before he or she is able to accurately perform fine and visual motor tasks utilizing his or her hands and eyes together (Case-Smith, Fisher, & Bauer, 1989).

In the field of education of children with CHARGE syndrome, one common suggestion is to incorporate frequent sensory breaks throughout the school day (Stelzer,

n.d.). During these sensory breaks, children may assume a variety of positions on the floor that reduce the demands of their postural muscles and their need to process vestibular and proprioceptive information. Most frequently, all educational demands are removed from the child during a sensory break (Stelzer, n.d.). Sitting in a beanbag chair or having contact with the floor provides increased tactile and proprioceptive information to their body to help them better understand where their body is in space (Brown, 2006). Having educated a large number of children with CHARGE syndrome, over time, staff in the Deafblind Program at Perkins School for the Blind<sup>1</sup> have asked the question "Can a child complete functional tasks in this position? Can working in positions on the floor that provide an increased proprioceptive input facilitate fine motor skills?"

### Three Positioning Interventions

Two positions that provide increased proprioceptive sensory input to the body are side-lying and supine.

<sup>1</sup> Perkins School for the Blind is a large corporate member of DbI

## Positioning Interventions



Natalie drumming in side-lying position



Jacob cutting with scissors in supine position



Grace playing with tongs in side-lying position

A side-lying position is defined as placing a child on his/her side with a support on his/her back. A supine position is defined as lying on one's back (Masin & Nicholson, 1990). These positions provide increased proprioceptive sensory input to a child's entire side or back, allowing him/her to feel more organized and physically stable, reducing the postural demands of working against gravity. Both side-lying and supine positions also reduce the need to use postural control of the head and neck to stabilize vision. When the child does not need to use his/her arms to support the upright position of their trunk, neck, and head, he/she has the freedom of movement to use his or her hands and fingers to engage in fine motor activity. A side-lying position facilitates movement across midline, for example when a child moves his/her left hand across his/her body to the right side. Therefore, side-lying and supine can be helpful positions to facilitate fine motor skills for children who have insults to their sensory systems and/or who have low muscle tone.

The purpose of this research study was to answer the questions posed by the occupational therapists at Perkins School for the Blind and determine the effectiveness of positioning interventions in improving fine motor skills for school-aged children with CHARGE syndrome and/or deafblindness.

The increase in fine motor skills can assist children with CHARGE syndrome and/or deafblindness to achieve optimal participation in school, self-care skills, and play.

### Clinical Findings

The participants in the study were seven students with deafblindness with residual vision, four of whom had CHARGE syndrome. All of the students had specific objectives related to fine motor skills in their Individualized Education Program (IEP). The students were ages four to thirteen years old enrolled in the Deafblind Program at Perkins School for the Blind. The students participated in thirty-minute occupational therapy sessions focusing on fine motor skills in all three positions twice a week for an average of ten weeks. Data were recorded on the following skills:

- Motor action that occurs on one side of the body
- Crossing the midline of the body
- Use of one hand
- Bilateral coordination, with both hands performing the same function
- Bilateral coordination, with each hand performing a separate function
- Use of residual vision during the motor task
- Engagement in self-stimulatory or other behavior that interferes with use of the hands

In addition, data were collected on the student's specific IEP objectives related to fine motor skills. The data collection methods were based on items from the Peabody Developmental Motor Scales (PDMS-2) and clinical observation (Folio & Fewell, 2000).

Measurable trends were observed when comparing the data recorded prior to the intervention and post intervention when the students were willing and able to participate. Overall, stability or progression of all fine motor skills was observed, with no regression of skills seen. Progression was defined as an increased frequency of engaging in a more advanced skill and a decreased frequency of engaging in an easier skill.

Crossing the midline of the body while performing motor action is a more advanced skill than performing action on only one side of the body. Engaging in any fine motor task with two hands (bilateral coordination) rather than one is also a more advanced skill. An example of bilateral coordination with both hands performing the same function would be using two hands to hold onto a ball when placing it into a container. An example of bilateral coordination with each hand performing a separate function would be using one hand to hold onto the ball and the other hand to hold on to the container.



POSITION	Same side action	Cross midline	Use one hand	Use two hands, same action	Use two hands, different actions	Use vision during motor action	TOTAL
Tabletop	0	4	2	2	5	6	19
Supine	0	2	4	0	4	5	17
Sidelying	0	4	4	0	5	6	23

Table 1: Improvements in Fine Motor Skills

One hand is manipulating the ball while the other is stabilizing the container. The latter of the two examples is a more advanced skill.

The specific number of students who improved in each skill in each position can be seen in Table 1. This table illustrates the number of participants out of seven who improved in each particular fine motor skill and in each position. The cells highlighted indicate the fine motor skills with the most improvement. Specifically, six out of the seven participants had improvements in using their residual vision during the motor action to complete a fine motor task when seated in a chair at a table or in a side-lying position.

When comparing the three different positions, the participants' fine motor skills improved most in the side-lying position, followed by seated at a tabletop, and then a supine position. Sitting at a table was most frequently associated with increased use of residual vision during the motor action whereas a side-lying or supine position was most frequently associated with increases in the participant's ability to use two hands to perform different actions as well as use residual vision during the motor action. No clear trends were seen in engagement of self-stimulatory behavior during the positioning intervention, likely due to a number of external factors.

Progression on all fine motor goals for each participant was also observed. Progress was defined as requiring less physical assistance to complete a fine motor task. However, the magnitude of progress differed for every student. Some students showed minimal progress while others exhibited more notable progress. These trends can be seen in Figure 1. For example, one student progressed from requiring moderate physical assistance (assistance for 45–59 % of the task) to place items into a container prior to the positioning intervention to requiring minimal to moderate physical assistance (assistance for 30–44 % of the task) at the post-test treatment

session. Another student progressed from requiring maximal physical assistance (assistance for 75–99 % of the task) to completing this task independently by the end of the research study. The highlighted lines in Figure 1 represent these two examples to illustrate the difference in magnitude of progress among participants.

This graph illustrates the amount of assistance required to complete a fine motor goal at the pre-test compared to the post-test treatment session. The following are explanations of the physical assistance required: Maximal = 75–99 %, Moderate-maximal = 60–74 %, Moderate = 45–59 %, Minimal-moderate = 30–44 %, Minimal

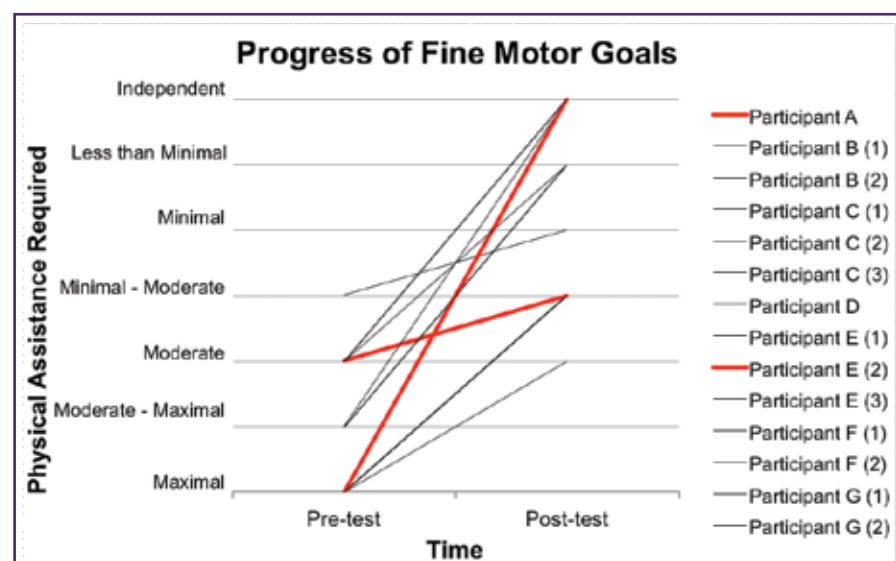


Figure 1

## Positioning Interventions

= 15–29%, Less than minimal = 1–14%, Independent = 0%. The highlighted lines indicate the two examples mentioned in the article.

### Conclusions

The results of this study answer the question that working in positions on the floor that provide an increased proprioceptive input *can* facilitate fine motor skills. Overall progress in fine motor skills was seen for each participant in all three of the positions indicating that fine motor skills can be addressed in multiple positions. Having a student practice fine motor tasks in a position that provides increased proprioceptive sensory input to his/her body may assist him/her in utilizing their hands and eyes together in a more productive manner.

However, it is important to keep in mind that the amount of progress achieved by each student is influenced by multiple factors, including the difficulty of the fine motor task, the amount of exposure and practice with the task, the amount of exposure and practice in the position, and motivation to complete the task. Below are some general recommendations to assist in using this intervention with a student or child with deafblindness and/or CHARGE syndrome.

### Recommendations

Provide the child with opportunities to change positions. Take note of which position the child prefers most and which is most functional for the child. Provide numerous opportunities throughout the day

for the child to engage in fine motor tasks in that optimal position.

Establish a consistent routine within therapy or classroom sessions. Create a specific area in the classroom or home where the child can assume specific positions to help the child anticipate expectations.

Observe and endeavor to understand the child's sensory seeking behaviors. Consulting with a trained professional, such as an occupational therapist, is recommended.

**For additional information, contact Samantha Kublin, OTD (skublin23@gmail.com)**

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# Quantitative Data Analysis

## Article #5 – Action Research in Deafblindness Series

Susan M. Bruce



This is the fifth article in the action research in deafblindness series by members of the Action Research Work Group of the Deafblind International (DbI) Research Network. Qualitative research designs may include narrative studies, phenomenological research, grounded theory research, ethnographic research, and case study research (Creswell, 2013). Action research is a problem solving form of research often involving multiple cycles of action and reflection. Case study design and elements of grounded theory design may be particularly amenable to action research in deafblindness. In this article, we will introduce some basic principles of qualitative data analysis that apply across qualitative study designs.

Qualitative analysis is an inductive process. Common data sources for qualitative analysis include: transcripts of videotaped observations, observation notes, reflection journals, open ended questions on a questionnaire or survey, collaboration or meeting notes, and a wide range of documents (such as yearly education plans or behavior plans). These data sources may address the learning of the individual who is deafblind and the learning of staff or family members. For example, teacher journals may inform the team about how the teacher experienced an intervention (what was easy or more difficult to implement or what seemed to work and what didn't).

The process of data coding involves reading and re-reading the data, writing notes or memos by hand or through a qualitative data coding software system (such as Atlas or Nvivo<sup>1</sup>) until all of the data have been accounted for. These codes are then examined for patterns or themes. These identified patterns or themes may then be renamed as the researcher collapses them into larger themes until the fewest number of themes that will address all the data have

been identified. Some data may fit within more than one theme and themes may interact with each other. In some cases, super themes or super-categories may emerge with sub-themes within.

In the process of data analysis, you may find that key words or phrases appear repeatedly. It is important to highlight these by hand or through a software analysis program. This linguistic information may give important clues about how participants perceive each other, a phenomenon, or about the impact of an intervention. In a participatory action research on civic engagement with six young deafblind adults, Bruce and Parker (2012) identified the following key words that the participants spoke or signed within the theme of *characteristics of effective change agents*:

“information, stories, experiences, communication, professional, pride, and proud” (p.22). These key words corresponded to key findings around the importance of being informed, having advocacy experiences, and to the sense of pride that comes from advocating for self and others.

While data analysis will address the research questions, the research questions are not the themes or

categories. Qualitative researchers must be open to identifying themes that are not suggested by their research questions, but are important to understanding the impact of the intervention. Sometimes the researcher may also begin the study with a few themes in mind due to expertise with the topic or the participants. For example, a researcher examining positive behavior supports for children with CHARGE Syndrome may anticipate that strategies to support anxiety-evoking situations will emerge. Still, most often themes emerge through the inductive process. The researcher must also look for evidence that is contradictory to identified themes.

Memo writing, the development of a data matrix, and member checks are important to qualitative analysis (Miles, Huberman, & Saldaña, 2014.) Memo writing occurs when the researcher jots down thoughts about the data. These are often helpful to grouping the data and to identifying themes. A matrix is a table that features the key themes listed along the top of the table with participants' or settings listed along the side of the table. In this way the matrix allows the researcher to record and

<sup>1</sup> <https://www.researchgate.net>

then to quickly view a summary of how the data varied across participants or settings. Member checks involve asking participants to review your findings for accuracy.

The qualitative researcher must be able to clearly define each theme or category and explain each theme's connection to the research questions and to other themes (Mertler, 2017). As the themes emerge, the qualitative researcher will want to record rich examples of the themes across data sources. In a study about positive behavior supports for adolescents who are deafblind, Nannemann, Bruce, and Covelli (2017) identified *adult use of language* as an important theme. One sub-theme within this larger theme was to recognize words or phrases and topics that tended to set off negative behaviors in students. Possible strategies included substituting words for trigger words or avoiding certain topics, especially on a difficult day. The researchers also described how adult use of language was used with Gail to redirect perseverative topics of conversation (such as frequent communication about the Wizard of Oz), to reduce anxiety in seemingly new situations by making connections to previous experiences (using phrases/signs such as "remember when" or "this is like" language) and to provide words/signs for the emotions she was experiencing.

It is important to be open to your data. Allow it to influence your thinking which may result in the need to revise the intervention, thus resulting in subsequent action research cycles (Pine & Bruce, 2010). In a study on dyadic interactions, the overarching research question was: How will interactions between older students with CHARGE syndrome and younger students with mixed etiologies change over time, in the context of an arranged interaction space? (Bruce, Zatta, Gavin & Stelzer, 2016). Joint attention was a theme

identified through the analysis of the observation videotapes. Joint attention challenges that were important to the quality of interactions in this study included: gaining visual attention of peer, the impact of positioning on peer attention, and allowing wait time that considered the length of the peer's visual latency. These identified challenges led to changes in the intervention such as suggesting that an older student count in order to allow sufficient wait time for his younger friend to respond or to sit when playing with certain objects/toys. These changes in the intervention then resulted in some improvements in interactions thus addressing the primary research question.

In qualitative research, we must be concerned about the trustworthiness of the findings. Trustworthiness may be supported by collecting information from multiple data sources. This allows for triangulation of the data. Careful and multiple readings of the raw data is critical to developing trustworthy findings. Using more than one rater allows for calculation of inter-rater reliability. A clearly articulated coding process, memo writing (that produces an audit trail), and member checks enhance the likelihood of trustworthy interpretation of the data. Finally, researcher positionality statements disclose the researcher's background especially as it relates to the research topic in an effort to be transparent about the relationship between the researcher and what is being researched. The qualitative researcher will want to save all paper and electronic records of the qualitative analysis process to support others who may want to know more about the study to better understand how coding occurred and how themes were developed. Many action research studies will require both quantitative and qualitative analyses. Practitioner researchers have an obligation to

be thoughtful about the reliability of findings based on quantitative data and the trustworthiness of findings based on qualitative data.

**For more information,  
contact Susan Bruce at:  
susan.bruce@bc.edu**

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# Learning through Action Research

Helle Buelund Selling and Anne Søbeye

This article highlights elements from an 'Action Research Project' carried out at the Centre for Deafblindness and Hearing Loss (CDH)<sup>1</sup> in Aalborg, Denmark.

At the CDH, the management, external collaborators and stakeholders are increasingly demanding more documentation, quality assurance and evidence as well as a clearer theoretical synthesis<sup>2</sup> from the employees.

Because of these new demands, a group of employees expressed a wish to develop their professional image, their professional practices and theoretical groundings.

In this article, we will describe how we worked with the desire for change, from a bottom up

perspective and thus explored the framework for dialogical processes that could contribute to fulfil the participants' desire. We wanted to examine whether action research could contribute to giving the employees a sense of co-ownership of all the "new measures". We believed that action research would create the framework for reflection and contribute to a sense of meaning and co-ownership among the co-researchers.

This is a much improved beginning.



Helle Buelund Selling



Anne Søbeye

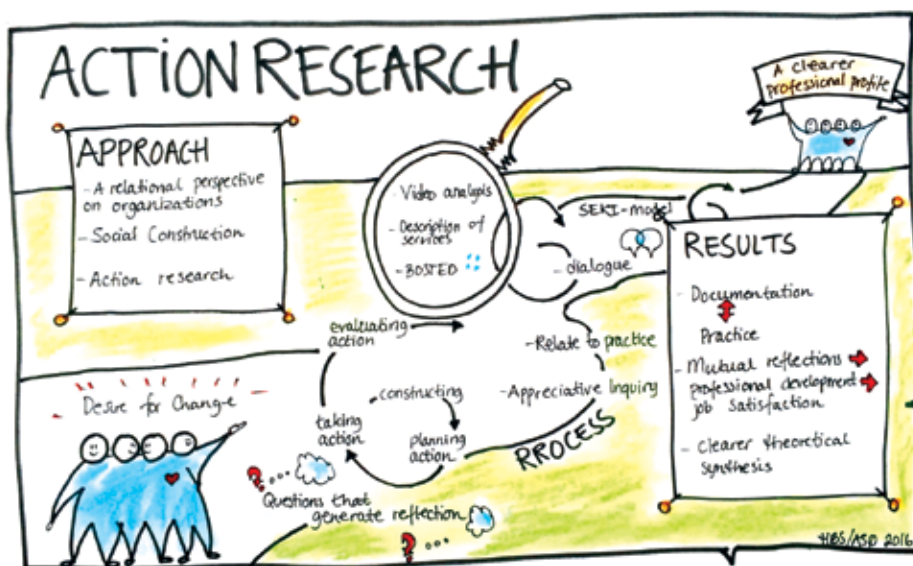
## Learning through actions

Action research can be considered an attempt to change a top down development strategy to a bottom up process based on the practices and understanding of the employees. Social psychologist Kurt Lewin emphasizes that the purpose of action research is to enable the co-researchers to handle situations or improve conditions previously perceived as obstacles (Duus et al., 2012, p. 82). According to Duus, action research is characterized by co-researchers learning through actions, projects and specific challenges or problems related to their daily work. It is a learning strategy and a learning method that helps professionals to be able to verbalize, understand and develop their profession from the inside.

Action research takes its departure in social constructionism<sup>3</sup> and has a dialogical approach<sup>4</sup> and a basic assumption that meaning and our understanding of the world are co-constructed in dialogues. Co-creation of meaning and understanding is understood as a fundamental element in human relations and social systems, based on the assumption that action and practice offer the possibility of empowering people.

An ongoing dialogic process among the co-researchers develops knowledge and recognition. The concept of knowledge is local and context interdependent with the co-researchers co-constructing knowledge (Aagaard, 2004, p. 518).

Based on an appreciative approach, action research focuses on successful experiences relating to the goals set in the project. The principle



<sup>1</sup> The Centre for Deafblindness and Hearing Loss ([www.cdhrn.dk](http://www.cdhrn.dk)) is a Small Corporate Member of DbI. CDH is a national service center for children, young people and adults with either deafblindness or hearing loss.

<sup>2</sup> Grimmen defines the theoretical and practical syntheses. It is described as "a theoretical synthesis", if the various elements of the profession's practice is based on extensive theory". If you talk about a "practical synthesis" you refer to the fact, that professional skills are tied to the people using them and tied to the situations they are used in "(Duus, G., Husted, M., Kildedal, K., Laursen, E. & Tofteng, D. 2012, p. 87-88).

<sup>3</sup> Social constructionism or the social construction of reality (also social concept) is a theory of knowledge in sociology and communication theory that examines the development of jointly constructed understandings of the world that form the basis for shared assumptions about reality.

<sup>4</sup> In a dialogical approach the process itself and the manner in which the process develops are interdependent.

of Appreciative Inquiry or AI<sup>5</sup> is to focus on successful actions the learner has already experienced, and use this experience in new learning and changing processes (Duus et al., 2012, p. 54).

### Taking action

We believe that each co-researcher possesses abilities, skills, resources, knowledge and experience based on their own practice and a knowledge about the professional approaches and methods they use in their daily work. Our intention was to facilitate processes enabling the co-researchers to co-produce new knowledge based on the knowledge they contributed themselves.

Together with the co-researchers, we agreed upon bringing three specific areas for examination into play: 1. the formal descriptions of the services; 2. the documentation system, BOSTED®<sup>6</sup>; and 3. video recordings of pedagogical activities. Using specific activities as a starting point allowed the co-researchers to verbalize and name professional approaches and methods in their own pedagogical practice.

### Powerful questions

In examining the approaches and the methods, we focused on the co-researchers' thoughts and perspectives and we strived to invite joint reflection by using various types of questions associated with specific intentions. We asked open-ended questions, to engage co-researchers to reflect and take a stand. Furthermore, we asked questions to provide a perspective on a theme, questions to clarify the next initiative and questions related to appreciative inquiry. In our preparation and evaluation of the individual actions, we also used meta-reflective questions (Høier,

M.O, Hersted, L. and Laustsen, L., 2011, p. 36 – 45).

The questions we asked in order to provide perspective on a certain theme contributed to broaden the understanding of the desire to archive a higher degree of a theoretical synthesis. The co-researchers mentioned that they felt that the desire for change could be regarded as a wish to “gain an increased awareness in relation to pedagogical practices” and to “narrow the gap between implicit and explicit knowledge”. They expressed a wish to be able to verbalize the professional methods and approaches applied by the unit in its pedagogical practice.

In order to discuss the desire to “narrow the gap between implicit and explicit knowledge”, we introduced the SECI model<sup>7</sup>, developed by the researchers Ikujiro Nonaka and Hirotaka Takeuchi (Nonaka, I. & Takeuchi, H., 1995, p. 62 – 70). The essence of the SECI model is that the acquisition and development of knowledge is a transformation process that binds different types of knowledge together including the transition between implicit/tacit, bodily experienced knowledge and explicit knowledge.

The SECI model created a framework to reflect upon the fact that the desire for change related to the experience of having tacit knowledge closely connected to bodily experiences. In order to meet the demand for a clearer theoretical synthesis, the co-researchers expressed a desire to be able to verbalize this knowledge in a formal and systematic language. Such a language would make it possible to describe and pass on the extensive theory that their professional practice is based on.

### Knowledge created within the project

In accordance to the desire to develop their professional image, the co-researchers highlighted four areas where new knowledge had been co-created within the project.

*Firstly* the co-researchers mentioned that they had become more aware of an interdependent coherence between written documentation and practices. The co-researchers feel that they are more aware of the pedagogical practices and that they use a more professional language in the written documentation, and this facilitates a methodical work process and the possibility of replicating work methods, which will be important in the pedagogical practices when dealing with the residents. One of the co-researcher said: “*I have become more aware of how I write about my work with the residents*”.

When examining in which situations the co-researchers felt that they had come closer to fulfilling their desire for change, they highlighted that they use professional terminology to describe the pedagogical practices in BOSTED® more often. The co-researchers perceive that it has become clearer to them what their professional expertise is and that there is a high degree of professionalism within the unit. Furthermore, the co-researchers experience that they verbalize implicit knowledge more frequently. Both changes support the development of new practices.

*Secondly*, it became clear that the desire for change was related to the wish to be able to verbalize the implicit subjective knowledge associated with bodily experiences. The co-researchers wanted to be able to pass knowledge to each

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<sup>5</sup> Appreciative Inquiry was developed by David L. Cooperrider and Suresh Srivastva. AI can be seen as an attempt to learn from and develop the areas, which an organization has already excelled at (Stegeager & Lauersen, 2013 p. 10).

<sup>6</sup> BOSTED® is a social educational IT tool developed specifically for documentation and knowledge sharing in social service centres.

<sup>7</sup> The SECI model distinguishes four knowledge dimensions – socialization, externalization, combination, and internalization – , which together form the acronym “SECI”.

other in a formal systematic language. Such a language made it possible to describe the extensive theory, which their professional practice is based on. For instance, we used video analysis to identify and verbalize the theoretical approaches and methods used the unit.

In addition to this, the co-researchers have experienced that a greater awareness has meant that it is now easier to replicate the work methods of each individual participant.

*Thirdly*, the co-researchers mentioned the importance of the culture in the unit in terms of what may support and facilitate the development of a clearer professional profile. Among other things, the co-researchers expressed that: *“We work in a unit where professional terminology is being used”*. This statement created a sense of pride and an awareness of already using professional terminology in their everyday language.

Thus, the way in which the co-researchers talk about the culture in the unit plays a significant part in co-creating the way in which they perceive the culture. The positive mental images of the future create a realization of the fact that there is already a culture supporting the use of professional terminology.

*Finally*, the co-researchers became more aware of the fact that professional development creates job satisfaction. They feel that the project has contributed to a higher degree of job satisfaction. This feeling links to a sense of an intensified focus on the pedagogical work and an increased awareness and recognition of the qualifications of the individual employee. As one of the co-researchers mentioned, *“I think that I have become more happy and satisfied because I have an increased focus on my professional skills”*.

Furthermore, there was a sense of us having co-created a clearer picture of the desire for change. This gave the co-researchers a greater sense of ownership and a high degree of involvement both in their daily work and in the action research project.

### Pros and cons

Action research challenges the understanding of communication as a dissemination of already formed attitudes and identities. Based on the hypothesis that the experience of joint ownership is essential for employees to manage changes and new demands, we wanted to explore to what extent action research contribute to a perceived ownership.

This project allowed the co-researchers to verbalize and develop the professional approaches and methods of the unit to a higher degree. The co-researchers expressed their experiences of development in such a manner that they more often verbalized and shared knowledge. In addition to this, they experience that they as a group are now able to make decisions on a joint different basis. Thus, a social change towards greater equality and empowerment has taken place by an increased ability to shape their own future.

The co-researchers found it very positive, that they had influence on the project’s direction. However, the intention of co-creation and co-responsibility for the success of the project also became a challenge. Throughout education in the established educational system, the co-researchers have experienced that success depends on the ability to find the right answer, a perception that they initially brought into the project. As one of the co-researchers expressed: *“it took a while before I realized what you were doing.”*

In relation to the challenges we experienced in the project,

we particularly will highlight the unfamiliar position as co-researcher in a project where success requires a special degree of participation, co-creation and dedication. The co-researchers felt unfamiliarity in co-creating goals, framework and content in a not clearly defined project as they didn’t know where the next step would lead.

As facilitators and co-researchers, we experienced the importance of metacommunication<sup>1</sup> about the position as co-researcher in action research. We became aware that it was essential to continually address these perceived frustrations in order to hinder them from becoming obstacles in fulfilling the desire for change.

Results from the project indicate that the strength of action research is its trust in and dependence on the competencies of the co-researchers and their abilities, skills, resources, knowledge and experience. The research is anchored by the co-researchers desire for change and this supports a higher degree of co-ownership and involvement.

We believe that action research offers a framework for an approach that creates co-ownership and the opportunity to co-create meaning in relation to, for example, new requirements. It is possible to work towards qualification and coping with an expressed desire for change, and the method gives employees an experience of actually influencing the organization’s continued development. At CDH, we share the experience of the project and our aims are that the results and experiences will be considered when new requirements are introduced to the employees.

**For further information, please contact: Helle Buelund (helle.buelund@rn.dk) or Anne Søbeye (anne.soebeye@rn.dk)**

<sup>8</sup> Metacommunication in this article refers to join reflection about the process. In other words, we talked about how we talked.

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## PRESS RELEASE:

# Deafblind writers' new book inspires hope & strength

A group of 28 writers touched by Usher syndrome tell their stories to end the isolation and to support research for a cure.

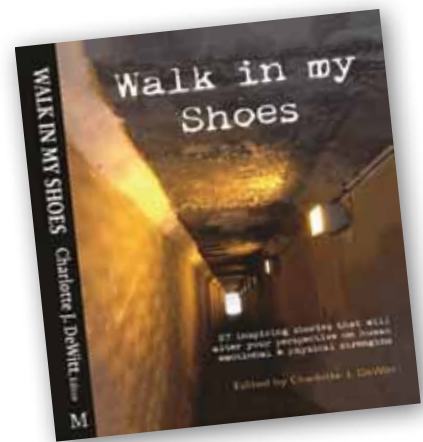
After two years of collaborative effort to create a book, it is finally complete! This book is a unique collection of 27 powerful stories by 28 individuals who are experiencing or witnessing the challenges of losing not one, but two senses: hearing and sight. The writers offer a glimpse into living with Usher syndrome, a progressive disease leading to blindness and deafness. It speaks to the more than 400,000 people worldwide dealing with Usher syndrome, to their families, to the professionals working with them, and to the rest of the world.

The writers come from all walks of life from the United States, Canada, and Mexico. They want to be seen and heard, even while their vision and hearing fail them. Their desire is to connect other people with Usher syndrome at annual Usher Syndrome Coalition conferences by promoting awareness in their communities and sharing this inspirational book. All proceeds from book sales will be donated to the Usher Syndrome Coalition to help fund scholarships and support research for a cure. These writers



inspire hope for anyone dealing with difficult life challenges. Even though they may not see or hear, they have so much to teach us about the human spirit, overcoming harsh obstacles and seeking equality in a society that does not understand them. Read their stories to see how they do it, to feel inspired, and to learn more about how you can help.

Ramona Rice, book creator and project manager, who has Usher syndrome type 2, conceived the idea to raise awareness about deaf



blindness, and facilitated the whole book project to share powerful, hopeful, humorous and compelling stories in and to support researchers to find a cure. She feels strongly that it will inspire many people around the world to unite and to make a difference for those suffering from deafblindness. She has received positive emails from 31 countries already! She is blessed with an amazing executive committee: Karen Duke/administrative manager, Randy DeWitt/editor, Marissa Postlewait/editor, Charlotte DeWitt/editor and Rose Sarkany/art designer and photographer.

### BOOK INFORMATION:

Trade Paperback ISBN: 978-1-945756-11-5 \$18.98; 282pp.

Ebook ISBN: 978-1-945756-12-2 \$8.99

Release Date: December 12, 2016

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### CONTACT INFORMATION:

Ramona Rice: rricetx@gmail.com

### WEBSITE INFORMATION:

Usher Syndrome Coalition:

<http://bit.ly/ushwalkinmyshoes>

<https://www.usher-syndrome.org/>

**Twitter:** @BKWalkinmyShoes

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 Sense  
 UK  
 (Gillian.Morbey@sense.org.uk)



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 The New York Institute  
 for Special Education  
 USA  
 (bkappen@nyise.org)



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 Royal Dutch Kentalis  
 NETHERLANDS  
 (F.Kat@kentalis.nl)



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 AUSTRIA  
 (green.lfo@usa.net)



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 Able Australia  
 AUSTRALIA  
 (gary.daly@ableaustralia.org.au)



**Stan Munroe**  
**Information Officer**  
 Canadian Deafblind Association  
 CANADA  
 (information@  
 deafblindinternational.org)



**Knut Johansen**  
**Development Officer**  
 Signo Vivo  
 NORWAY  
 (knut.johansen@signo.no)



**Carolyn Monaco**  
**Strategic Planning Officer**  
 Canadian Deafblind Association  
 CANADA  
 (carolyn.monaco@sympatico.ca)



**Dennis Lolli**  
**Diversity Officer**  
 Perkins International  
 USA  
 (Dennis.Lolli@Perkins.org)

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DbI's partner organizations, ICEVI and WFDB have observer status on the DbI Board:

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 of People with Visual Impairment  
 Lord Colin Low  
 Contact: colin.low@rnib.org.uk  
 Website: www.icevi.org

World Federation of  
 the Deafblind  
 Geir Jensen  
 Contact: geir.jensen@fnadb.no  
 Website: www.wfdb.eu

## Representing Large Corporate Members



**Gillian Morbey**  
Sense  
UK  
(Gillian.Morbey@  
sense.org.uk)



**Elvira Edwards**  
Senses Australia  
AUSTRALIA  
(elvira.edwards@  
senses.org.au)



**Sian Tesni**  
CBM (Christoffel  
Blindenmission)  
UK  
(sian.tesni@  
cbm.org.uk)



**Andy Kerr**  
Sense Scotland  
UK  
(akerr@sense  
scotland.org.uk)



**Cathy Proll**  
Canadian Deafblind  
Association  
Ontario Chapter  
CANADA  
(cproll@cdba  
ontario.com)



**Frank Kat**  
Royal Dutch Kentalis  
NETHERLANDS  
(F.Kat@kentalis.nl)



**Kaye Collard**  
Able Australia  
AUSTRALIA  
(Kaye.Collard@  
ableaustralia.org.au)



**Pilar Gomez**  
ONCE  
SPAIN  
(pgv@once.es)



**Jutta Wiese**  
German Deafblind  
Consortium  
GERMANY  
(jutta.wiese@  
blindeninstitut.de)



**Marianne Riggio**  
Perkins International  
USA  
(marianne.riggio@  
perkins.org)



**Rossano Bartoli**  
Lega del Filo  
d'Oro  
ITALY  
(info@legadelfilo  
doro.it)



**Roxanna  
Spruyt-Rocks**  
DeafBlind  
Ontario Services  
CANADA  
(ceo@deafblind  
ontario.com)

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## Representing DbI Networks



**Andrea Wanka**  
CHARGE Network  
Stiftung St. Franziskus,  
Heiligenbronn  
GERMANY  
(aw@andrea-  
wanka.de)



**Liz Duncan**  
Acquired Deafblindness  
Network  
UK  
(Liz.Duncan@  
sense.org.uk)



**Emma Boswell**  
Usher Network  
UK  
(Emma.Boswell@  
sense.org.uk)



**Joe Gibson**  
Outdoor Network  
NORWAY  
(deafblindoutdoors  
@gmail.com)



**Ricard Lopez**  
European  
Deafblind Network  
SPAIN  
(fecoce@fecoce.org)



**Nadja Högner**  
Usher Network  
GERMANY  
(nadja.hoegner@  
hu-berlin.de)



**Simon Allison**  
Youth Network  
UK  
(simon.allison@  
sense.org.uk)

## Representing Small Corporate Members



**Carolyn Monaco**  
Canadian Deafblind  
Association  
CANADA  
(carolyn.monaco@  
sympatico.ca)



**Marleen Janssen**  
University of  
Groningen  
NETHERLANDS  
(h.j.m.janssen@  
rug.nl)



**Ricard Lopez**  
Spanish Federation  
of Deafblindness  
(FESOCE)  
SPAIN  
(rlopez@  
sordoceguera.com;  
fesoce@fesoce.org)



**Gloria Rodriguez-Gil**  
Perkins Latin America  
and Caribbean Office  
ARGENTINA  
(gloria.rodriguez@  
perkins.org)



**Jackie Brennan**  
Overbrook School for  
the Blind  
USA  
(jackie@obs.org)



**Ursula Heinemann**  
Österreiches Hilfswerk  
für Taubblinde  
AUSTRIA  
(ursiheinemann@  
usa.net)



**David Murray**  
Deafblind Australia  
AUSTRALIA  
(david.murray@  
deafblind.org.au)



**Knut Johansen**  
Signo  
Døvblindesenter  
NORWAY  
(knut.johansen@  
signo.no)



**Bernadette Kappen**  
The New York  
Institute for  
Special Education  
USA  
(bkappen@  
nyise.org)



**Lars Solbe**  
Center for  
Deafblindness and  
Hearing Loss  
DENMARK  
(laejs@rn.dk)



**Koh Poh Kwang**  
Lighthouse School  
SINGAPORE  
(kohpohkwang@  
lighthouse.edu.sg)



**Marie-Jose  
vandenDriessche**  
Royal Dutch Visio  
NETHERLANDS  
(MarieJosevan den  
Driessche@visio.org)



**Trish Wetton**  
Forsight Australia  
AUSTRALIA  
(trish.wetton@  
forsight.net.au)



**Maria Creutz**  
Nordic Centre  
for Welfare and  
Social Issues  
SWEDEN  
(maria.creutz@  
nordicwelfare.org)



**Mirko Baur**  
Tanne Schweizerische  
Foucnation  
fur Taubblinde  
SWITZERLAND  
(mirko.baur@  
tanne.ch)

# Secretariat News

## New DbI Secretariat – Able Australia



We would like to introduce the new DbI Secretariat hosts – Able Australia with Gary Daly as the Secretary. Able Australia is a not for profit service provider to people with deafblindness and to people with multiple disabilities. Able Australia<sup>1</sup>, celebrating their 50th Anniversary in 2017, is committed to the

Australian deafblind community and are looking forward to assisting the International deafblind community as part of the DbI Secretariat role.

Gary Daly has worked with Able Australia for 7 years and is Special Projects Coordinator and the Conference Coordinator of the 17th Deafblind International World Conference to be held in Australia from the 12th to 16th August 2019. You can contact Gary as follows: Gary.Daly@ableaustralia.oprg.au

Able Australia would like to thank the previous DbI Secretariat of Matthew Wittorff, Bronte Pyett, Elvira Edwards & CEO – Debbie Karasinski from Senses Australia for their enormous contribution to the DbI Secretariat role over the past 8 years.

### MEETINGS

On March 16th, 2017 the DbI Management Committee met in London, UK for the first meeting with the new DbI Secretariat.

The meeting discussions were centered around the follow up from the 2016 DbI Management Committee meeting in Orlando, Florida; information about the 9th DbI European Conference in Denmark in September 2017 and the DbI Management Committee Networks structure.

### DBI BOARD AND MANAGEMENT COMMITTEE

#### Changes to the DbI Board

Henriette Hermann Olesen from Centre for Dovblindhed og Horetab has stepped down and Lars Søbeye from Centre for Dovblindhed og Horetab has replaced Henriette in this position.

Matthew Wittorff relinquished the DbI Secretariat position and has stepped down from the Board. Senses Australia retains a seat on the Board as a Large Corporate member.

#### Changes to Dbi Management Committee

Matthew Wittorff & Bronte Pyett have stepped down from their roles Secretariat.roles.

Henriette Hermann Olsen has stepped down from the DbI Management Committee and her the role as the DbI Network Coordinator.

### MEMBERSHIP

DbI recognizes that the success it achieves worldwide greatly depends on the support of its individuals and corporate members to promote awareness and services. Becoming a member of DbI is as simple as going online through our website – [www.deafblindinternational.org](http://www.deafblindinternational.org) and completing the required application form.

Worldwide memberships as of May 2017	
Large Corporate	14
Small Corporate	45
Mini Corporate	3
Library	8
Individual	102

### HOW TO KEEP CONNECTED

You can keep in touch with colleagues a number of different ways:

Via the Networks on the website: [www.deafblindinternational.org/networks.html](http://www.deafblindinternational.org/networks.html)

 [www.facebook.com/dbiint](https://www.facebook.com/dbiint)



<sup>1</sup> Able Australia ([www.ableaustralia.org.au](http://www.ableaustralia.org.au)) is a large corporate member of DbI.

# DbI Review – Sponsorship Guidelines

Corporate Member Organizations are invited to sponsor future editions of *DbI Review*. If interested, check out the Guidelines below.

The purpose of Deafblind International (DbI) is to bring together professionals, researchers, families, people who are deafblind and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children and adults who are deafblind of all ages.

One activity that assists in promoting the purpose of DbI is via the “*DbI Review*” biannual publication. This publication is coordinated and edited by the DbI Information Officer.

The opportunity should be provided to all corporate members and other organisations that support the Mission and Vision of DbI to sponsor the *DbI Review*. In order to achieve this, sponsorship information will be published in each edition of the *DbI Review* and also on the website.

## Applying for Sponsorship of an Edition of the *DbI Review*

Applicants requesting to sponsor should have similar social values as DbI and have an interest in the well being of individuals who are deafblind.

The DbI Management Committee (ManCom) must endorse all sponsorships. The Secretariat will inform applicants of the outcome of their request for sponsorship following a decision by ManCom.

Applications should be sent to the DbI Secretariat. The Secretariat will then work with the Information Officer to ensure that the details of the sponsorship commitments by both the sponsor and DbI are followed through on.

## Sponsorship Levels, Costs and Entitlements of *DbI Review*

### Level 1 Sponsorship = 8000 Euro

There can be only one Level 1 sponsor. If a Level 1 sponsor is approved, then there will be no other levels of sponsorship permitted within that *DbI Review* edition. A Level 1 sponsor will have the following entitlements within one edition of *DbI Review*:

- Exclusive sponsorship rights of that *DbI Review*
- Name on bottom of front cover of *DbI Review*
- Supply photograph to be used on front cover of *DbI Review*
- Have input into the theme for the publication
- Full page advert
- 3 articles (related to individuals who are deafblind)
- 25 x extra copies of *DbI Review*

### Level 2 Sponsorship = 4000 Euro

There can be only two Level 2 sponsors. A Level 2 sponsor will have the following entitlements to one edition of *DbI Review*:

- Half page advert
- 2 articles (related to individuals who are deafblind)
- 15 x extra copies of *DbI Review*

### Level 3 Sponsorship = 2000 Euro

There are no limits to how many Level 3 sponsors can be approved. A Level 3 sponsor will have the following entitlements to one edition of *DbI Review*:

- Quarter page advert
- 10 x extra copies of *DbI Review*



For all levels of sponsorship, DbI reserves the right to not publish submissions that we deem for any reason to be unsuitable, unlawful, or objectionable, such as but not limited to the content of the material (for example, the usage of inappropriate language), the subject matter, the timeliness or relevance of the material, or reasons related to intellectual property, among others.

## Successful Applicants

Successful applicants will be notified no later than one month following their application submission to the publication of the *DbI Review* they wish to sponsor.

Applicants to accept or decline the sponsorship no later than four and a half months prior to the publication of the *DbI Review*.

The agreed amount of sponsorship funds will be transferred to the nominated account no later than 3 months prior to the publication date of the *DbI Review* they will sponsor.

Funding can only be accepted in Euros and not in any other currency.



DIVERSITY



NETWORKS



SOCIAL MEDIA

# STRATEGIC PLAN

JUN 2015 - AUG 2019



DEAFBLIND INTERNATIONAL



## STRATEGIC PRIORITIES JUNE 2015 - AUGUST 2019



### Diversity

DbI will become a diverse organisation in all aspects including membership and Board representation.

**1** PRIORITY ONE



### Share Knowledge

DbI will support our networks to share knowledge and develop partnerships.

**3** PRIORITY THREE



### Social Media & Information Technology

DbI will invest in technology and social media to connect with our members and the global community.

**2** PRIORITY TWO

## Honorary Officers

<p><b>President</b> <b>Gillian Morbey</b> Sense UK Email: Gillian.Morbey@sense.org.uk</p> <p><b>Vice-President</b> <b>Bernadette Kappen</b> The New York Institute for Special Education Email: bkappen@nyise.org</p> <p><b>Vice-President &amp; Treasurer</b> <b>Frank Kat</b> Royal Dutch Kentalis Email: F.Kat@kentalis.nl</p> <p><b>Immediate Past President</b> <b>William Green</b> Email: green.ifo@usa.net</p> <p><b>Secretary</b> <b>Matthew Wittorff</b> Senses Australia Email: dbisecretary@deafblindinternational.org</p>	<p><b>Strategic Plan Officer</b> <b>Carolyn Monaco</b> Canadian Deafblind Association Email: carolyn.monaco@sympatico.ca</p> <p><b>Information Officer</b> <b>Stan Munroe</b> Canadian Deafblind Association Email: munroes@seaside.ns.ca</p> <p><b>Development Officer</b> <b>Knut Johansen</b> Signo Email: knut.johansen@signo.no</p> <p><b>Diversity Officer</b> <b>Dennis Loli</b> Perkins International Email: Dennis.Loli@Perkins.org</p>
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## Large Corporate Members

<p><b>AUSTRALIA</b> <b>Able Australia</b> Kaye Collard Email: Kaye.Collard@ableaustralia.org.au Website: www.ableaustralia.org.au</p> <p><b>Senses Australia</b> Elvira Edwards Email: Elvira.Edwards@senses.org.au Website: www.senses.org.au</p> <p><b>CANADA</b> <b>Canadian Deafblind Association Ontario Chapter</b> Cathy Proll Email: cproll@cdbaontario.com Website: www.cdbaontario.com</p> <p><b>DeafBlind Ontario Services</b> Roxanna Spruyt-Rocks Email: ceo@deafblindontario.com Website: www.deafblindontario.com</p> <p><b>DENMARK</b> <b>Interfond</b> Pierre J. Honoré Email: pjh.interfond@mail.dk</p> <p><b>GERMANY</b> <b>CBM – Christoffel Blindenmission</b> Monika Brenes Email: Monika.Brenes@cbm.org Website: www.cbm.org</p> <p><b>German Deafblind Consortium</b> Jutta Wiese Email: jutta.wiese@blindeninstitut.de</p>	<p><b>ITALY</b> <b>Lega del Filo d'Oro</b> Rosanno Bartoli Email: info@legadelfilodoro.it Website: www.legadelfilodoro.it</p> <p><b>SPAIN</b> <b>ONCE</b> Pilar Gomez Email: pgv@once.es Website: www.once.es</p> <p><b>SWEDEN</b> <b>Resurscenter Mo gård</b> Michael Karlsson Email: michael.karlsson@mogard.se Website: www.mogard.se</p> <p><b>THE NETHERLANDS</b> <b>Royal Dutch Kentalis</b> Frank Kat Email: F.Kat@kentalis.nl Website: www.kentalis.nl</p> <p><b>UNITED KINGDOM</b> <b>Sense</b> Gillian Morbey Email: Gillian.Morbey@sense.org.uk Website: www.sense.org.uk</p> <p><b>Sense Scotland</b> Andy Kerr Email: akerr@sensescotland.org.uk Website: www.sensescotland.org.uk</p> <p><b>USA</b> <b>Perkins International</b> Marianne Riggio Email: Marianne.riggio@perkins.org Website: www.perkins.org</p>
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## Mini Corporate Members

<p><b>ETHIOPIA</b> <b>Ethiopian National Association of the Deafblind (ENADB)</b> Roman Mesfin Email: enadb@ethionet.et</p>	<p><b>MALAWI</b> <b>Visual Hearing Impairment Membership Association (VIHEMA Deafblind Malawi)</b> Ezekiel Kumwenda E-Mail: vihema.deafblindmalawi@gmail.com</p> <p><b>African Federation of Deafblind (AFDB)</b> Ezekiel Kumwenda Email: afdb.secretariat@gmail.com</p>
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## Networks

<p><b>Acquired Deafblind Network</b> <b>Liz Duncan</b> Email: Liz.Duncan@sense.org.uk Website: http://adbn.deafblindinternational.org</p> <p><b>CHARGE Network</b> <b>Andrea Wanka</b> Email: aw@andrea-wanka.de Website: http://chargenetwork.deafblindinternational.org</p> <p><b>Communication Network</b> <b>Marleen Janssen</b> Email: h.j.m.janssen@rug.nl Website: http://communication.deafblindinternational.org</p> <p><b>EDbN</b> <b>Ricard Lopez Manzano</b> Email: rlopez@edbn.org Website: http://edbn.deafblindinternational.org</p>	<p><b>Ibero Latin American Network</b> <b>Vula Ikonomidis</b> Email: vula2004@hotmail.com Website: http://iberolatinerican.deafblindinternational.org</p> <p><b>Network of the Americas</b> <b>Marianne Riggio</b> Email: Marianne.Riggio@Perkins.org Website: http://americas.deafblindinternational.org</p> <p><b>Outdoor Network</b> <b>Joe Gibson</b> Email: deafblindoutdoors@gmail.com Website: http://outdoornetwork.deafblindinternational.org</p> <p><b>Research Network</b> <b>Walter Wittich</b> Email: walter.wittich@umontreal.ca Website: http://research.deafblindinternational.org</p>	<p><b>Rubella Network</b> <b>Nigel Turner</b> Email: nigel.turner@sense.org.uk Website: http://rubella.deafblindinternational.org</p> <p><b>Social-Haptic Communication Network</b> <b>Dr. Riitta Lahtinen &amp; Russ Palmer</b> Email: riitta.lahtinen@icloud.com; rpalmer2@tskali.co.uk Website: http://socialhaptic.deafblindinternational.org</p> <p><b>Tactile Communication Network</b> <b>Paul Hart</b> Email: phart@sensescotland.org.uk Website: http://tcn.deafblindinternational.org</p>	<p><b>Usher Network</b> <b>Emma Boswell &amp; Nadja Hoegner</b> Email: Emma.Boswell@sense.org.uk; nadja.hoegner@googlemail.com Website: http://usher.deafblindinternational.org</p> <p><b>Youth Network (DbIYN)</b> <b>Simon Allison</b> Email: simon.allison@sense.org.uk Website: http://dbiyn.deafblindinternational.org</p>
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## Small Corporate Members

<p><b>ARGENTINA</b> <b>Perkins Latin America and Caribbean Office</b> Gloria Rodriguez-Gil Email: gloria.rodriguez@perkins.org</p> <p><b>AUSTRALIA</b> <b>Deafblind Australia</b> David Murray Email: info@deafblind.org.au Website: www.deafblind.org.au</p> <p><b>Forsight Australia</b> Trish Wetton Email: forsight.us@forsight.net.au Website: www.forsightaustralia.org.au</p> <p><b>AUSTRIA</b> <b>Österreichs Hilfswerk für Taubblinde</b> Christa Heinemann Email: c.heinemann@zentrale.oehbt.at Website: www.oehbt.at</p> <p><b>CANADA</b> <b>CDBA National</b> Carolyn Monaco Email: carolyn.monaco@sympatico.ca Website: www.cdbanational.com</p> <p><b>The Lions McInnes House – Group Home for Deafblind Persons</b> Laurie Marissen Email: LionsMcInnesHouse@rogers.com</p> <p><b>Canadian National Institute for the Blind (CNIB)</b> Email: Sherry Grabowski@cnib.ca Website: www.cnib.ca</p> <p><b>CHINA HONG KONG</b> <b>Resource Centre for the Deafblind</b> <b>The Hong Kong Society for the Blind</b> Doreen Mui Email: doreen.mui@hksb.org.hk Website: www.hksb.org.hk</p> <p><b>CROATIA</b> <b>Mali dom – Zagreb</b> Darija Udovicic Mahmuljin Email: darija@malidom.hr Website: www.malidom.hr</p> <p><b>CYPRUS</b> <b>Pancyprion Organization of the Blind</b> Christakis Nikolaidis Email: pot@logos.cy.net</p> <p><b>DENMARK</b> <b>Center for Deaf</b> Karin Moreau Andersen Email: kma@cfd.dk Website: www.cfd.dk</p>	<p><b>Socialstyrelsen</b> Trine Skov Uldall Email: tu@socialstyrelsen.dk Website: www.dovblindfoet.dk</p> <p><b>Danish Parents Association</b> Vibeke Faurholt Tel: (45)+98854332 Email: faurholt@mail.tele.dk</p> <p><b>The Center For Deafblindness and Hearing Loss (CDH)</b> Lars Søbye Email: laejs@rn.dk Website: www.dbc.rn.dk</p> <p><b>FINLAND</b> <b>The Finnish Deafblind Association</b> Sanna Nuutinen Tel: +358 40 529 3439 +358 40 604 7477 Email: sanna.nuutinen@kuurosokeat.fi Website: www.kuurosokeat.fi</p> <p><b>FRANCE</b> <b>RFPS-ANPSA</b> Dominique Spriet Email: president@anpsa.fr</p> <p><b>GREECE</b> <b>Hellenic Association of Deafblind "The Heliotrope"</b> Diamanto-Toula Matsa Email: diamatsa@gmail.com</p> <p><b>ICELAND</b> <b>National Institute for the Blind, Visually Impaired and the Deafblind</b> Estella D. Björnsdóttir Email: estella@midstod.is</p> <p><b>INDIA</b> <b>Sense International (India)</b> Akhil Paul Email: akhil@senseindia.org Website: www.senseindia.org</p> <p><b>IRELAND</b> <b>The Anne Sullivan Centre</b> Grace Kelly Hartnett Email: gracekellyh@annesullivancentre.ie Website: www.annesullivan.ie</p> <p><b>NEW ZEALAND</b> <b>Royal New Zealand Foundation for the Blind (RNZFB)</b> Jill Baldwin Email: jbbaldwin@blindfoundation.org.nz Website: www.rnzfb.org.nz</p> <p><b>NICARAGUA</b> <b>Asociacion de Sordociegos de Nicaragua</b> Mireya Cisne Caceres E-mail: sordociegosnicaragua@hotmail.com</p>	<p><b>NORWAY</b> <b>Signo kompetansesenter</b> Anne Lise Hoydahl Email: anne.lise.hoydahl@signo.no</p> <p><b>Signo Vivo</b> Knut Johansen Email: knut.johansen@signo.no Website: www.signodovblindesenter.no</p> <p><b>Eikholt</b> Roar Meland Email: roar.meland@eikholt.no Website: www.eikholt.no</p> <p><b>Statped</b> Bitten Haavik Ik Dahl Email: Bitten.H.Ikdahl@statped.no Website: www.statped.no</p> <p><b>National Advisory Unit of deafblindness</b> Eva Hirsti Email: eva.hirsti@unn.no</p> <p><b>Regional Center for people with deafblindness</b> Eva Hirsti eva.hirsti@unn.no</p> <p><b>RUSSIA</b> <b>Deaf-Blind Support Fund "Con-nection"</b> Dmitry Polikanov Email: d.polikanov@so-edinenie.org Website: www.sso-edinenie.org</p> <p><b>SINGAPORE</b> <b>Lighthouse School</b> Koh Poh Kwang Email: kohpohkwang@lighthouse.edu.sg Website: www.lighthouse.edu.sg</p> <p><b>SPAIN</b> <b>Spanish Federation of Deafblindness (FESOC)</b> Ricard Lopez i Manzano Email: fesoce@fesoce.org Website: www.fesoce.org</p> <p><b>APASCIIDE – Spanish Association of Parents of Deafblind People</b> Dolores Romero Chacon Email: apasce@apasce.org Website: www.apasce.org</p> <p><b>SWEDEN</b> <b>The Swedish Resource Centre for Matters Regarding Deafblindness</b> Michael Karlsson Email: michael.karlsson@mogard.se Website: www.nkadb.se</p> <p><b>Nordic Welfare Centre</b> Maria Creutz Email: nvcdb@nordicwelfare.org Website: www.nordicwelfare.org</p>	<p><b>Specialpedagogiska Skolmyndigheten</b> Mia Martini Email: mia.martini@spsm.se Website: http://www.spsm.se</p> <p><b>SWITZERLAND</b> <b>SZB Beratungsstellen für hörschbehinderte und taubblinde Menschen</b> Mäde Müller Email: mueller@szb.ch Website: www.szb.ch</p> <p><b>Tanne, Schweizerische Stiftung für Taubblinde</b> Mirko Baur Email: mirko.baur@tanne.ch Website: www.tanne.ch</p> <p><b>THE NETHERLANDS</b> <b>Bartimeus</b> Betty van Wouw Email: bwouw@bartimeus.nl Website: www.bartimeus.nl</p> <p><b>Kalorama, Centrum voor doofblinden</b> Els Peters Email: e.peters@kalorama.nl Website: www.kalorama.nl</p> <p><b>Koninklyke Visio</b> Marie-José van den Driessche Email: MarieJosevandenDriessche@visio.org Website: www.visio.org</p> <p><b>University of Groningen</b> Marleen Janssen Email: h.j.m.janssen@rug.nl</p> <p><b>UNITED KINGDOM</b> <b>Sense International</b> Website: www.senseinternational.org</p> <p><b>Scene Enterprises CIC</b> David Sutton Email: david.sutton@sceneenterprises.org.uk Website: www.sceneenterprises.org.uk</p> <p><b>UNITED STATES OF AMERICA</b> <b>The New York Institute for Special Education</b> Bernadette Kappen Email: bkappen@nyise.org Website: www.nyise.org</p> <p><b>Overbrook School for the Blind</b> Jackie Brennan Email: jackie@obs.org Website: www.obs.org</p> <p><b>Texas School for the Blind &amp; Visually Impaired – Texas Deafblind Project</b> Cyril Miller Email: cymiller@tsbi.edu Website: www.tsbi.edu/deaf-blind-project</p>
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